Developing a patient- centred care pathway for paediatric critical care in the Western Cape

by

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Declaration

I, Peter William Hodkinson hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Peter W Hodkinson

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ABSTRACT

Developing a patient centred care pathway for paediatric critical care in the Western Cape

Peter Hodkinson February 2015

Background: Emergency care of critically ill or injured children requires prompt identification, high quality treatment and rapid referral. This study examines the critical care pathways in a health system to identify preventable care failures by evaluating the entire pathway to care, the quality of care at each step along the referral pathway, and the impact on patient outcomes.

Methods: A year-long cohort study of critically ill and injured children was performed in Cape Town, South Africa, from first presentation until paediatric intensive care unit admission or emergency centre death, using a modified confidential enquiry process of expert panel review and caregiver interview. Outcomes were expert panel assessment of quality of care, avoidability of death or PICU admission and severity at PICU admission, identification of modifiable factors, adherence to consensus standards of care, as well as time delays and objective measures of severity and outcome.

Results: The study enrolled 282 children: 85% medical and 15% trauma cases (252 emergency admissions, and 30 children who died at referring health facilities). Global quality of care was graded poor in 57(20%) of all cases and 141(50%) had at least one major impact modifiable factor. Key modifiable factors related to access and identification of the critically ill, assessment of severity, inadequate resuscitation, delays in decision making and referral, and access to paediatric intensive care. Standards compliance increased with increasing level of healthcare facility, as did caregiver satisfaction. Children presented primarily to primary health care (54%), largely after hours (65%), and were transferred with median time from first presentation to PICU admission of 12.3 hours. There was potentially avoidable severity of illness in 74% of children, indicating room for improvement.

Conclusions and Relevance:

The study presents a novel methodology, examining the quality of paediatric critical care across a health system in a middle income country. The findings highlight the complexity of the care pathway and focus attention on specific issues, many amenable to suggested interventions that could reduce mortality and morbidity, and optimize scarce critical care resources; as well as demonstrating the importance of continuity and quality of care throughout the referral pathway.

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Staff
I'd like to specifically thank all of the healthcare workers and facility managers for their willing participation and interest in the study, even with the insight that the study would likely criticize and focus on negative aspects of the services delivered, in the face of often extreme patient loads and demands from all directions. Particular thanks to the RCWMCH PICU staff who put up with our team and helped in many ways, and to the RCWMCH EC staff. Thanks also to EMS staff, particularly the record staff (and Mr Sauls) who were always prompt and helpful, as well as EMS management for their support and the use of an EMS vehicle for some of the data collection.

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Research Team The research project which this thesis describes, was not an individual effort, it was a large collaborative project spanning several years and two continents. I am indebted to the entire research team, and acknowledge every member and their roles (in no specific order) as below:

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CONTRIBUTIONS

As stated above a research project of this nature is clearly not all my own work and I need to formally acknowledge the contribution of others. I will be the first author on several papers that will be generated from this work, having performed the data analysis myself, and drafted all the manuscripts de novo. Much of the analysis, interpretations and critical review of these manuscripts, as well as insights and interpretations developed in several grant applications by the research team, overlaps with the material in this thesis.

My role was as the clinical fellow, as such I developed and actioned the original grant proposal into this research methodology, I was primarily responsible for designing the data capture tools (data entry processes, interview questionnaires, and the review process. I oversaw and chaired the consensus standards development process, developed the modifiable factor lists and determined the review process and algorithms. I helped to train the research team, and oversaw and collated the data collection. I performed the data cleaning and most of the analysis, with support from the team especially around the multivariable regression.

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Study conception and design: AA, AW, LW, PH, RP, ME, RG.
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CONTENTS

ABSTRACT III

ACKNOWLEDGEMENTS IV

CONTRIBUTIONS VI

CONTENTS VII

LIST OF TABLES IX
LIST OF FIGURES XI
LIST OF APPENDICES XII
LIST OF CASE STUDIES XII
LIST OF ABBREVIATIONS XIII
DEFINITIONS XV

1 INTRODUCTION 17

CASE STUDY 1 17
1.1 BACKGROUND 19
1.2 CONTEXT 21
1.3 AIMS AND OBJECTIVES 26

2 LITERATURE REVIEW 27

2.1 LITERATURE SEARCH METHODOLOGY 27
2.2 CHILDHOOD MORTALITY AND MORBIDITY IN SOUTH AFRICA 28
2.3 THE PATHWAY AND PROCESS OF CRITICAL CARE 34
2.4 QUALITY OF CARE IN PAEDIATRIC HEALTHCARE 42
2.5 THE CONFIDENTIAL ENQUIRY AND OTHER LONGITUDINAL STUDY METHODOLOGIES 44

3 METHODOLOGY 55

3.1 PILOT STUDY 55
3.2 POPULATION AND STUDY SAMPLE 56
3.3 ASCERTAINMENT 57
3.4 DATA MANAGEMENT: ONLINE DATABASE 62
3.5 REVIEW PROCESS 62
3.6 DATA ANALYSIS 66
3.7 ETHICAL CONSIDERATIONS AND PATIENT CONSENT 67
3.8 DATA VERIFICATION 67
3.9 CONCLUSION 68

4 DEMOGRAPHICS AND DESCRIPTION OF COHORT 69

4.1 DEMOGRAPHICS 69
4.2 DIAGNOSIS 69
4.3 ACCESS TO CARE ISSUES 74
4.4 DISCUSSION: DEMOGRAPHICS; DIAGNOSIS AND ACCESS TO CARE 76

5 OUTCOME AND QUALITY ASSESMENT 81

5.1 OUTCOME OBJECTIVE 81
5.2 EXPERT REVIEWER ASSESSMENT 82
5.3 MULTIVARIABLE REGRESSION 90
5.4 SYSTEM ISSUES 91
5.5 CAREGIVER PERCEPTION AND SATISFACTION 94
5.6 DISCUSSION: OUTCOME ASSESSMENT 96

6 PATHWAY AND DELAY 99

6.1 INTRODUCTION 99
6.2 PATHWAY DESCRIPTION 99
6.3 FACILITIES INVOLVED IN CRITICAL PATHWAY 101
6.4 PATHWAY ACCESS AND ROUTING SPECIFICS 102
6.5 DELAYS 110
6.6 DISCUSSION 118
6.7 CONCLUSION 124
CASE STUDY 2 125

7 DEATHS PRIOR TO PICU 127

7.1 LITERATURE REVIEW 127
7.2 RESULTS 128
7.3 DISCUSSION 135

8 MODIFIABLE FACTORS 137

8.1 BACKGROUND 137
8.2 RESULTS 140
8.3 DISCUSSION 149

9 STANDARDS FOR PAEDIATRIC EMERGENCY CARE IN CAPE TOWN 151

9.1 BACKGROUND 151
9.2 DEVELOPMENT OF CONSENSUS STANDARDS 152
9.3 RESULTS: SYSTEM WIDE COMPLIANCE WITH STANDARDS 160
9.4 DISCUSSION 164
CASE STUDY 3 166

10 MAIN DISCUSSION 167

10.1 OVERVIEW OF KEY FINDINGS 167
10.2 CONTEXTUALIZATION WITH OTHER STUDIES 171
10.3 DISCUSSION OF RESEARCH METHODOLOGY 173
10.4 CHALLENGES AND INSIGHTS FROM THE DATA COLLECTION AND ANALYSIS PROCESS 180

11 RECOMMENDATIONS 187

11.1 SYSTEM WIDE INTERVENTIONS 188
11.2 PAEDIATRIC AND PHC “SYSTEM” INTERVENTIONS 191
11.3 RECOMMENDATIONS FOR SPECIFIC LEVELS 193
11.4 RECOMMENDATION CONCLUSION 197
11.5 FOLLOW UP RESEARCH 200

12 CONCLUSION 203

13 REFERENCES 205

APPENDICES 221

List of Tables

Table 1-1 RCWMCH Medical EC Statistics for 2012 (personal communication H. Buys, 2013) 23
Table 2-1 Common modifiable factors (by responsible person) identified in children who died (Stephen, CR, et al,2013)[88] ... 32
Table 2-2 Common modifiable factors (by place) in children who died (Stephen, CR, et al ,2013)[88] 32
Table 2-3 Confidential Enquiry into Maternal and Child Health (CEMACH) definitions for avoidable factors in childhood deaths (Pearson, G. A., 2008)[53] 46
Table 3-1 Inclusion and Exclusion Criteria 56
Table 3-2 List of Potential Modifiable Factors 63
Table 3-3 Definitions of Impact of Modifiable Factors 64
Table 3-4 Algorithm used to calculate agreement between internal reviewers for Global Assessment of Care 65
Table 3-5 Algorithm used to calculate agreement between internal reviewers for Avoidability of Death/ PICU Admission/ Severity 65
Table 4-1 Baseline characteristics of the enrolled children 70
Table 4-2 Medical patient's diagnosis and age grouping 71
Table 4-3 Trauma Aetiology/ Diagnosis by Age Group 72
Table 4-4 Principal diagnosis and age group of enrolled children 72
Table 4-5 Access to care issues 75
Table 4-6 Comparison of Pathways to Care cohort to Western Cape population 77
Table 5-1 Objective outcomes of children admitted to the Paediatric Intensive Care Unit 81
Table 5-2 Thirty day outcomes for all children admitted to PICU according to main diagnosis 82
Table 5-3 Objective Outcomes for PICU admissions by main diagnosis 82
Table 5-4 Outcomes of expert clinical review 83
Table 5-5 Adverse Reviewer Gradings for Each Diagnostic Group# 85
Table 5-6 Reviewer Grading for each age group of cases 85
Table 5-7 Details of Facilities relative to Quality of Care 86
Table 5-8 Details of EMS transfers relative to Quality of Care 87
Table 5-9 Cases where there was disagreement requiring consensus meeting discussion for each of the four key outcomes 88
Table 5-10 Kappa Scores for main review outcome variables (comparing each reviewer to consensus) 89
Table 5-11 Clinical outcomes of multivariable linear regression for medical PICU admissions 90
Table 5-12 Outcomes of multivariable logistic regression on children with medical conditions 91
Table 5-13 Summary of health system themes identified in enrolled children 92
Table 5-14 Reviewer assessment of quality of care and caregiver satisfaction with care and communication for each type of facility 94
Table 5-15 Reviewer assessment of quality of care and caregiver satisfaction with care and communication for each type of EMS transfer 95
Table 6-1 Number, type and timing of health care facilities visited from initial presentation to PICU admission or death .. 103
Table 6-2 Summary of Caregivers planned response to emergency 104
Table 6-3 Detailed Description of Patients and Pathways according to routing within RCWMCH (for those admitted to PICU (excluding 30 deaths prior PICU)) 109
Table 6-4 Detailed Description of outcomes for patients according to routing within RCWMCH (for those admitted to PICU (excluding 30 deaths prior PICU)) 110
Table 6-5 Time from illness onset to initial presentation, transfer and admission to Paediatric ICU 111
Table 6-6 Delay Data for each Diagnostic Group 112
Table 6-7 Detailed Delays including only those who were admitted to PICU (excludes 30 deaths prior PICU) 113
Table 6-8 PICU Assessment and Admission Delay for PICU Admissions 114
Table 6-9 PICU Admission Delays for Cape Town and non-Cape Town Cases 114
Table 6-10 Delay intervals within different facility levels (for medical patients only) 115
Table 6-11 EMS Time Intervals for different types of call and crew composition. 117
Table 6-12 Effect of new EMS prioritization policy on time intervals 118
Table 7-1 Description of Deaths prior to PICU admission 129
Table 7-2 Details of 15 patients who died prior to RCWMCH admission (at CHC or Hospital) 131

Table 7-3 Details of 15 patients who died at RCWMCH prior to PICU admission 132
Table 7-4 Details of the children who died in PICU (in order of PICU length of stay)... 134
Table 8-1 Modifiable factors underlying SA deaths of mothers and children according to three national mortality audits (Bradshaw, D., et al., 2008)[87] 137
Table 8-2 Modifiable Factor Categorization from ChIP SA (Child Healthcare Problem Identification, 2013[229] 138
Table 8-3 Modifiable Factors Applied in each Facility or EMS Assessment 139
Table 8-4 Most frequent modifiable factors at each impact level 142
Table 8-5 Major impact modifiable factors and negative clinical review outcomes 143
Table 8-6 Ten most frequent Modifiable Factors for all Facilities 144
Table 8-7 Top 10 Modifiable Factors for Non Hospital Facilities (GP, clinic and CHC).. 145
Table 8-8 Top 10 Modifiable Factors for District and Regional Hospital Facilities (District and Regional Hospitals; RCWMCH: EC, Wards, Operating Theatre).. 146
Table 8-9 Top 10 Modifiable Factors for RCWMCH Facilities (EC, Wards, Operating Theatre) 147
Table 8-10 Top 10 Modifiable factors identified for each type of EMS transfer 148
Table 9-1 Provincial Emergency Care Standards Taskforce Composition 152
Table 9-2 Condensed and Graded Standards for Paediatric Critical Care 155
Table 9-3 Standards Compliance across levels of facilities and EMS types 161
Table 9-4 Compliance with Standards across Standard Diagnosis Groups 163
Table 10-1 Summary of key issues at frequent sites 168
Table 10-2 Key Issues identified across the health system 169
Table 10-3 Assessment of the value and efficiency of each element of the PTC study 181
Table 11-1 System Issues for intervention (non-emergency) 192
Table 11-2 Summary of Recommendations 198
Table 0-1 Summary and visualization of each case gradings and pathway 236
Table 0-2 Vitals Signs for Each Step of Pathway 275
Table 0-3 Standards for CHC 275
Table 0-4 Modifiables for CHC 276
Table 0-5 Standards for EMS Transfer 278
Table 0-6 Modifiables for EMS Transfer 279
Table 0-7 Standards for RCWMCH EC.. 280
Table 0-8 Modifiables for RCWMCH EC 281
Table 0-9 Combined Modifiable Factors 282
Table 0-10 Reviewer Assesment: Facility & EMS... 283
Table 0-11 Reviewer Assessment... 283
Table 0-12 Grading schematic key... 313
Table 0-13 Visualization of reviewer gradings for global quality of care and consensus process 314

LIST OF FIGURES

FIGURE 2-1 GLOBAL AND WHO REGIONAL PROGRESS TOWARDS THE ACHIEVEMENT OF HEALTH RELATED MDGS 5 (WORLD HEALTH ORGANIZATION, 2013)[78] 28
FIGURE 2-2 TRENDS IN UNDER-FIVE MORTALITY RATES IN SOUTH AFRICA 1998 TO 2011 AND THE 2015 MDG TARGET (NATIONAL COORDINATING COMMITTEE FOR THE MILLENNIUM DEVELOPMENT GOALS, 2013)[74] 29
FIGURE 2-3 NUMBER OF CHILD DEATHS UNDER 5 YEARS OF AGE BY SELECTED CAUSES OF DEATH (BRADSHAW D, D. R. E., LAUBSCHER R, 2012)[77] 33
FIGURE 2-4 SUMMARY OF THREE-DELAY MODEL OF DELAY TO CARE 34
FIGURE 2-5 FACTORS INFLUENCING ACCESS TO CARE DECISIONS 35
FIGURE 2-6 SUPPLY AND DEMAND BARRIERS TO HEALTH CARE UTILIZATION (ENSOR, T. AND S. COOPER,2004)[116] 36
FIGURE 2-7 SPECTRUM OF HEALTH SERVICES FOR CHILDREN (KISSOON, N., ET AL. ,2009)[161] 41
FIGURE 3-1 SCHEMATIC OF PATHWAYS TO CARE RESEARCH PROJECT 58
FIGURE 3-2 SCHEMATIC OF REVIEW PROCESS 59
FIGURE 3-3 SCREENING AND ENROLMENT PROCESS 61
FIGURE 3-4 PATIENT ENROLMENT THROUGHOUT THE COLLECTION PERIOD 62
FIGURE 4-1 MONTHLY DIAGNOSIS PROPORTIONS FOR THE YEAR OF DATA COLLECTION 73
FIGURE 4-2 DIAGNOSIS SPREAD ACROSS THE YEAR OF DATA COLLECTION 73
FIGURE 5-1 AVOIDABILITY OF ICU ADMISSION OR DEATH FOR ALL CASES 84
FIGURE 5-2 INTERNAL REVIEW GRADINGS PRIOR TO CONSENSUS MEETINGS 88
FIGURE 5-3 CONSENSUS GRADINGS OF OVERALL QUALITY OF CARE THROUGHOUT THE YEARLONG STUDY PERIOD 89
FIGURE 6-1 SIMPLIFIED OVERALL SCHEMATIC OF PATHWAYS PATIENTS 100
FIGURE 6-2 FREQUENCY OF VISITS TO INDIVIDUAL FACILITIES OVER STUDY PERIOD (FREQUENTLY VISITED FACILITY TYPES ONLY SHOWN) 101
FIGURE 6-3 SCHEMATIC OF THE REFERRAL PATHWAY FOR TRAUMA PATIENTS ADMITTED TO PAEDIATRIC INTENSIVE CARE 105
FIGURE 6-4 SCHEMATIC OF THE REFERRAL PATHWAY FOR MEDICAL PATIENTS ADMITTED TO PAEDIATRIC INTENSIVE CARE 106
FIGURE 6-5 GRAPHICAL REPRESENTATION OF EMS CALL OUT AND TRANSFER PROCESS AND TIME INTERVALS 116
FIGURE 8-1 NUMBER OF MAJOR IMPACT MODIFIABLE FACTORS PER CASE 140
FIGURE 8-2 NUMBER OF MODERATE IMPACT MODIFIABLE FACTORS PER CASE 141
FIGURE 9-1 COMPLIANCE WITH STANDARDS ACROSS FACILITY LEVELS AND EMS TYPES 162

LIST OF APPENDICES

I. ETHICS APPROVALS (PATHWAYS TO CARE; PH PHD) 222

II. PROVINCIAL & CITY OF CAPE TOWN APPROVALS FOR RESEARCH 230

III. VISUALIZATION OF PATHWAYS AND REVIEWER GRADING 236

IV. PRESENTATIONS ON PTC WORK: POSTERS & CONFERENCE 243

V. PHD PROTOCOL – DEVELOPING A PATIENT CENTERED CARE PATHWAY FOR PAEDIATRIC CRITICAL CARE IN THE WESTERN CAPE 244

VI. PROTOCOL: PATHWAYS TO CARE FOR CRITICALLY ILL CHILDREN 261

VII. CASE STUDY (73) : SZ 274

VIII. CAREGIVER INTERVIEW SCHEDULE 287

IX. QUANTITATIVE DATA COLLECTED FOR EACH CASE 291

X. SCREENSHOTS OF ONLINE DATABASE 294

XI. PAEDIATRIC EMERGENCY CARE STANDARDS: 300

XII. MODIFIABLE FACTORS 310

XIII. VISUALIZATION OF EXPERT REVIEWER GRADINGS FOR EACH CASE 313

LIST OF CASE STUDIES

CASE STUDY 1 17
CASE STUDY 2 125
CASE STUDY 3 166

LIST OF ABBREVIATIONS

ALS	Advanced Life Support
BLS	Basic Life Support
CDC	Community day centres
CEMACH	Confidential Enquiry into Maternal and Child Health
CEMD	Confidential Enquiry into Maternal Deaths
CESDI	Confidential Enquiry into Stillbirths and Deaths in Infancy
CHC	Community Health Centre
ChIP	Child Healthcare Problem Identification Program
CMACE	Centre for Maternal and Child Enquiries
CT	computed tomogram scan
DOA	Dead on arrival
EC	Emergency Centre
EM	Emergency Medicine
EMS	Emergency Medical Services
EMSSA	Emergency Medicine Society of South Africa
ETAT	Emergency Triage Assessment and Treatment
GP	General Practice
HCP	Health care provider
HDACC	Health Data Advisory and Co-ordination Committee
HIC	High income country
HIV	human immunodeficiency virus
ICU	Intensive Care Unit
ILS	Intermediate Life Support
IMCI	Integrated Management of Childhood Illness
IMR	Infant mortality rate
IMR	infant mortality rate
IO	intra-osseous
IV	intravenous
LMIC	Low and middle income countries
MDG	Millennium Development Goal
MVA	Motor vehicle accidents
NG	naso-gastric
NHI	National Health Insurance
NHS	National Health Service
PCP	Pneumocystis pneumonia
PFS	Paediatric Flying Squad
PHC	Primary health care
PICU	Paediatric intensive care unit
PIM2	paediatric index of mortality 2
PPIP	Perinatal Problem Identification Program
PTC	Pathways to Care
QOC	Quality of care
RCWMCH	Red Cross War Memorial Children's Hospital

SA	South Africa
SATS	South African Triage Score
TB	tuberculosis
U5MR	under five mortality rate
UK	United Kingdom
US	United States of America
WHO	World Health Organization

DEFINITIONS

IMR	infant mortality rate - number deaths in children under a year of age per 1000 live births [1]
Infant	child under one year of age[1]
Neonate	child under four weeks of age[1]
PIM2	Paediatric Index of Mortality 2 Score – physiological scoring system which gives a predicted mortality for a child based on specified physiological indices, usually on admission to an intensive care unit[2]
U5MR	under five mortality rate – number of children under five years old who die in a year per 1000 live births in the same year[1]
z-score	statistical measure of deviation from a mean, in the context of this work used in weight for age comparisons; WHO defines a z-score of < -2 as underweight, and < -3 as severely underweight/ malnourished [3]

1 INTRODUCTION

CASE STUDY 1

SZ was a 3 week old baby girl who lived with her mother and two siblings in a corrugated iron "shack" in a low socio-economic suburb of Cape Town. Their home language was Xhosa, their monthly income was under R 2 500 a month. They lived approximately six km from a community health centre (CHC).

On a Sunday evening in February, SZ became suddenly ill, with diarrhoea and rapid breathing, followed by vomiting. By midnight her mother, MZ, was concerned and begged a neighbour with a car to take them to the CHC approximately 6km away. MZ says she didn't even consider calling an ambulance – she knew they would take too long and didn't even know the number.

They arrived at the CHC around midnight. Security directed MZ to open a folder. She struggled to rouse the sleeping clerk and eventually was given a folder, and waited in a queue for a doctor who was busy with another child. As soon as the doctor saw SZ he gave her face mask oxygen and tried to put up an intravenous (IV) line, was unsuccessful on her arms and head, but eventually successful on her leg (intra-osseous(IO) access) although this was undocumented by the doctor). SZ was assessed as having severe gastro-enteritis with dehydration and shock: "Lethargic and possible aspiration pneumonia" according to the (brief) doctor's notes. She was given a single bolus of 20 ml/kg 0.9% NaCl solution, and a half-strength Darrow's IV maintenance solution was started. There were no further notes or evidence of re-assessment for the following two hours in the CHC. The mother was told nothing at this stage but overheard the doctor discussing "lack of blood" and "black blood". SZ started vomiting, and a nasogastric (NG) tube was inserted (initially unsuccessfully). MZ didn't understand much of the doctor's discussion (in English) but a nurse explained that an ambulance had been called to take SZ to Red Cross War Memorial Children's Hospital (RCWMCH).

Some two and a half hours after SZ's arrival at the CHC, an ambulance was called which arrived 90 minutes later with an Advanced Life Support (ALS) crew. They found the child attached to a maintenance infusion of half-strength Darrow's solution connected to an IO needle (not running), no oxygen, and with an NG tube in situ. SZ was assessed by the Emergency Medical Services (EMS) crew as shocked and dehydrated. She was transported by the EMS crew with face mask oxygen. No note was made as to whether the IO infusion was now running.

SZ arrived at RCWMCH (approximately 15 km away) almost five hours after first presentation to the CHC (31 minutes after leaving the CHC). At the RCWMCH Emergency Centre (EC), she was assessed as hypothermic (32.8 °C), shocked, and acidotic (pH <6.8). Resuscitation with non-rebreather face mask oxygen, two 20ml/kg boluses of IV fluid (0.9% NaCl) and ceftriaxone was instituted just five and a half hours after her first CHC presentation. She was reassessed an hour later and found to be responding and warming up. Investigations showed she likely had a severe pneumonia and was in septic shock. She was discussed (telephonically) with the RCWMCH paediatric intensive care unit (PICU) staff, who accepted her, advised

starting her on a dobutamine infusion, but there was no PICU bed immediately available for her, but they would make arrangements to free a bed up by discharging a stable patient.
Four hours after arrival at RCWMCH, SZ was admitted to PICU. She was found to be in septic shock. Initial investigations showed a pH of 7.15, and lactate 8.1. She was intubated and resuscitated but despite maximal therapy died just over 48 hours after PICU admission.

In order to give some insights to the depth and detail of information across the health system collected and analysed in the study, this is a summary (compiled from review of medical records from various facilities and EMS, and supplemented by information from caregiver interview conducted with the mother on the day following the child's admission to RCWMCH PICU) of an individual case from the Pathways to Care database. Detailed timelines, outcome assessments, and review assessments as made by the expert panel are detailed in **Appendix VII**.

1.1 BACKGROUND

"Emergencies occur everywhere, and each day they consume resources regardless of whether there are systems capable of achieving good outcomes."[4] Kobusingye 2005

Critically ill and injured patients are those with life threatening processes which can result in morbidity and mortality unless managed appropriately and timeously.[5] Early and appropriate management of the critically ill patient requires a multi-faceted health system approach to provide early access to high quality emergency care, systems for safe and efficient transfer, and specialized facilities and staff to deliver optimal care.[6,7] Critical care describes the process that starts at the time of recognition of a patient who is physiologically unstable, and will require high level monitoring and constant management, provided by all healthcare workers from the first identification, through to definitive care and ultimately until discharge to home.[8,9] Or more specifically "all aspects of care for patients with sudden, serious, reversible disease,…and includes triage and emergency medicine, hospital systems, quality of care and Intensive Care Units (ICU)"[6] (Baker 2009). Paediatric critical care is a complex and resource-intensive process. In many high income country (HIC) settings, acute emergency paediatric critical illness and injury is becoming a less frequent presentation as health systems develop. However in low and middle income countries (LMIC) where there are many barriers to optimal care of such patients, life threatening illness or injury is still an all too frequent presentation.[7] When, where, and how often does care for critically ill children fail, in particular the initial component taking the patient from presentation through to intensive care unit admission? Studies around the world have shown the effectiveness of interventions to improve specific aspects of critical care[10-14], but there is a lack of evidence about the relative importance and frequency of care failures at different points in the care pathway. Identification of care failure at any point throughout the pathway is essential for prioritising allocation of resources to achieve improvements in critical care and a reduction in child deaths.

Many children in LMICs die unnecessarily from common acute conditions despite decades of healthcare experience and knowledge.[15] While the primary intervention may be prevention targeting maternal education, access to clean water and adequate sanitation, housing, access to food, and then health issues such as immunization and access to primary care,[15] there will always be a need for emergency and critical care of acutely ill and injured children. Critical care systems in the LMICs may be inadequate with consequent high mortality and morbidity (including an increased need for and prolonged stay in a PICU).[16] Various studies have demonstrated the effectiveness of interventions to improve specific aspects of emergency and critical care, including those aimed at the community, early recognition at the PHC level, as well as hospital emergency care and for specific presentations including sepsis[17], trauma[18], and fluid therapy. Research on interventions for sepsis, for example, demonstrates that effectiveness is related to the timing and appropriateness of therapy (antibiotics) to improve outcomes in adults,[19,20] as well as in children.[21] Even for a single condition it is clear that compliance with interventions is extremely difficult to achieve, even in highly resourced settings.[22-25] Quality and speed through health systems is related to the variety of conditions encountered. Improvement in management of all children with life threatening illness or injury is likely to be even more challenging.[26] Given that critical care encompasses care until discharge, it is noteworthy that several studies illuminate post discharge mortality and this is an important aspect to be borne in mind that many studies (including this study) do not have adequate follow up data to review post discharge mortality. [27,28]

Families and caregivers, particularly in lower socio-economic areas, are often only able to access local health facilities which will need to stabilize the patient and refer to an appropriate facility. This "pathway" to care is a longitudinal route through the health care system, from first access, usually through a PHC facility, possibly with an ambulance trip, and sometimes via a smaller hospital, to the specialist hospital able to offer definitive care to such children. Even in extremely well-resourced settings, there is much evidence that the care even within a single institution for a single condition or disease may not always be optimal.[29-31] To improve the system, we need to understand the current situation: the steps in the process of delivering care, the time taken at each step, and the nature and the quality of care provided during each step. Highlighting foci for effective quality improvement interventions in paediatric emergencies has the potential to provide significant benefit to acutely unwell children, especially in resource-poor settings where the need is greatest, and the health services poorest,[32] as well as in more affluent countries where delivery of recommended care may still be difficult.[33]

While there is a significant body of research in high income settings focussed on identification of acutely ill children,[34-39] and numerous clinical pathway improvements to optimise care,[40] there has been far less attention on lower resource settings.[41] Although healthcare in South Africa (SA) is generally of a higher standard than much of Africa, there may be islands of excellence around some largely urban facilities, with gross inequities in the services available and the quality thereof in between.[42] The Western Cape, and Cape Town in particular, offer arguably some of the best health services in South Africa (and in Africa) with good and improving mortality and morbidity figures to demonstrate this,[43] although still distant from the care and outcomes expected in high income countries.

Quality of healthcare is not easy to measure. The literature is replete with studies that attempt to quantify quality of care in a health facility/ health service or even for universal application.[31,44-49] Some tools seem to work better than others, many rely on expert opinion, and nearly all are dependent on review of documentation of medical care, often assessing quality of documentation as much as care.[50] In addition, paediatric critical illness is a relatively uncommon entity in HIC settings where many of the studies originate.[51] Studies on the quality of emergency care and the referral systems in an entire health system are lacking. Yet anecdotal evidence from public sector clinicians in Cape Town would suggest there are deficits in emergency care delivery by the health care system even within the Cape Town Metropol - which is relatively well staffed with a network of nurse-run clinics, CHCs, PHC outpatient facilities (some offering 24 hour emergency care), district and regional hospitals, and several tertiary specialist hospitals.

These problems are known to exist but are inadequately quantified. To address these, a research program was developed using a novel combination of qualitative and quantitative methodology. This was initially based on the methodology of the United Kingdom (UK) "Confidential Enquiry" into maternal mortality and paediatric mortality,[52,53] where there is an in-depth investigation of the records and circumstances around a death and a panel consensus is reached as to the main issues and potential remedial factors to prevent the recurrence and learn from the errors of the system (without attributing blame to individuals). In addition to this framework, our research incorporated an interview with the parent/ caregivers of each child studied to gain their insights of the healthcare system, and the assessment of standards of paediatric emergency care which would allow an objective assessment of the care.

1.2 CONTEXT

1.2.1 Paediatric Emergency Care in South Africa and the Western Cape Province

Since 2003, the speciality of emergency medicine (EM) has developed in SA and particularly in the Western Cape, although without a specific focus on emergency services for children.[54] Children make up close to a third of urban emergency consultations and are managed by PHC practitioners in many of these settings, the majority without specific training or skills in paediatrics beyond limited undergraduate exposure.[55] A subset of nursing staff have received further training in either Emergency Triage Assessment and Treatment (ETAT) or Integrated Management of Childhood Illness (IMCI)[56-59] (both courses focus on the identification and referral of the ill child more than the care thereof). In some facilities these registered nurses will see childhood emergencies, although with limited scope to deal with critically ill or injured children (who they would refer to an onsite doctor in most cases). In hospital ECs childhood emergencies are seen mixed with adults by medical practitioners, some specialists in EM, others unspecialized medical officers and junior doctors. EM specialists and those in training will have spent at least six months in paediatrics, as well as having participated in paediatric specific ALS training, but the majority of doctors and nurses are likely more comfortable with adult emergencies. Paediatricians may be available for emergencies in larger facilities, but primarily for ongoing in-patient care.

Although the Western Cape is one of the wealthiest provinces in SA, there is much inequity in socio-economic and health status. One third of the population live below international poverty lines, and a quarter of children live in informal and overcrowded houses.[43,60] The urban poor of the Western Cape (largely black African and mixed race or "coloured" people) largely live in informal housing, and are prone to infectious diseases such as chest infections, gastro-enteritis and tuberculosis (TB), as well as trauma (high rates of violence and injuries are prevalent in Western Cape communities and children are prone particularly to motor vehicle accidents, burns, and abuse).[61,62] Data from 2002 showed that access to good healthcare in the Western Cape was limited by inadequate emergency staff, distance and transportation to health care (especially after hours) and distrust in under-resourced PHC facilities.[61]

The Western Cape has a rapidly expanding population due largely to rural to urban migration from other provinces. At the time of the study (2011) the Western Cape population was around 5.5 million (of SA's 50 million total) of whom 1.8 million (33%) were children (<18 years).[43] Health services to the public sector (*i.e.* largely for those unable to afford private sector medical services) are provided by a network of PHC clinics who refer to district and regional hospitals, including RCWMCH, the only dedicated paediatric hospital in the province with a 22-bed PICU.

In a 2001 study[63], after hours PHC services for children in Cape Town have been shown to be inadequate for the demand, with likely little change since then. Most children were seen mixed with adults by generalists with little prioritization of acuity. Up to 80% of paediatric cases were not regarded as emergencies, two thirds were medical and just six percent were referred (subsequent to this study triage South African Triage Score (SATS) has been introduced and mandated at after-hours PHC facilities).[63,64] More recent data show that paediatric cases comprise 24% of daily attendees at PHC facilities in the metropol, most being seen after-hours and 35% of paediatric cases being regarded as emergencies and 10% referred for further management.[55]

RCWMCH is the largest paediatric facility in SA and is one of two tertiary hospitals in Cape Town serving children (Tygerberg Hospital drains the northern side of Cape Town and the northern and central Western Cape, and has a neonatal ICU, as well as a 10-15 bed PICU). RCWMCH has almost 300 beds (including 22 PICU beds) and is the referral hospital as well as the regional hospital for much of the south-western metropol of Cape Town and the southern districts of the province. RCWMCH deals with a varied population from low/ middle income urban dwellers, to desperately poor urban slum dwellers and rural referrals as well as a small proportion of the wealthy population. The hospital is able to provide a wide range of services on many fronts, such as paediatric cardiothoracic surgery and transplantation, requiring a high level of technology and technical expertise, as well as PICU.

Children are referred to RCWMCH from around the province, but primarily from within the Cape Town metropol by: several hundred independent general practitioners; 109 nurse-run clinics, 36 doctor-run community day centres (CDC) (in “office hours” only); nine doctor-run 24 hour CHC; and five hospitals. Transfer of patients is facilitated by an established EMS system, comprising a fleet of approximately 140 ambulances across the province and transferring over 400 000 patients annually (personal communication S. DeVries, 2013). These are staffed predominantly by crew with basic/ intermediate life support skills and only 10% paramedics with ALS skills. In addition there are three dedicated paediatric transfer vehicles, known as the Paediatric Flying Squad (PFS) vehicles, and an air transfer service mainly for long distance transfers.

Emergency admissions to the RCWMCH PICU are primarily from the EC of the RCWMCH, which is divided into separate medical and trauma units. The RCWMCH EC has developed from the 1970s (with similar demographics to the present day unit, common medical admissions in 1972 were pneumonia, bronchiolitis, meningitis, febrile convulsions and gastro-enteritis)[65] to a large unit, divided into medical and trauma sections, with an annual attendance in 2012 of 38 000 medical and 10 500 trauma patients and 21 000 admissions (personal communication RCWMCH management, 2013).

During the study period the RCWMCH medical EC used their own triage tool, based on ETAT – a World Health Organization (WHO) algorithm to identify and manage sick children.[13,56,66] ETAT uses an ABCD approach to delineate different problem areas and prioritise into colour categories according to urgency and has been studied in the RCWMCH setting of a pure paediatric medical emergency unit,[67] although the SATS tool also incorporates a paediatric element which has been similarly evaluated, but in more general mixed ECs[68] and it remains a contention as to which tool is most appropriate. The practicalities of the patient load and acuity means that many critically ill children are often “assumed red, un-triaged, direct to Med Reg”[69] and so bypass triage direct to the resuscitation room.

Statistics for the RCWMCH medical EC for 2012 (which covers most of the study period) give the breakdown of the different triage categories (personal communication H. Buys, 2013) as per Table 1-1 which is similar to the 2007 and 2009 analysis of Buys[67]. Also of interest is that 291 (0.8%) were admitted to PICU, and 9058 (23.9%) admitted to hospital. Two thirds (25 008) of patients had been referred to RCWMCH, the rest were self-referred (or brought by EMS direct). Further data from Bonaconsa[69] gives the disposition of medical EC patients as 45% to short stay wards; high care and PICU, 10% (of which just 3% PICU); discharged home 30%; wards 3% (and 12% un-documented disposition) and is likely more accurate for the period.

Table 1-1 RCWMCH Medical EC Statistics for 2012 (personal communication H. Buys, 2013)

Triage group (ETAT)	Number of patients	%
Red	2150	5.7
Orange	13107	34.6
Yellow	2943	7.8
Green	19700	52.0
Total	37900	100.0

The flow of emergency patients in the RCWMCH has been examined in a detailed study.[69] There are complex flow patterns depending on the acuity of patients. Clearly identified high acuity patients (for example those intubated or escorted in by EMS personnel who have identified patient as SATS "red" triage) are routed direct to the resuscitation bays, while other children are generally first screened by a security guard at the entrance, and then triaged soon after in a dedicated triage area before being routed to either a general waiting area for lower acuity patients to be seen in a consulting room, or to other specialist/ outpatient areas of the hospital. Time of day dictates staffing and patient load and so impacts on the routing (after 23h00 almost all patients regardless of acuity are seen by a single doctor consulting from the resuscitation bays). Once seen, patients are either discharged, kept in an overnight emergency ward (for observation prior to early discharge, or in many cases while awaiting a ward bed), admitted to an inpatient speciality ward bed, or to PICU. In most cases, despite acuity, resources and flow limitations in the hospital dictate a delay before admission to a ward or PICU, often while waiting for a bed to be freed up or staff to be mobilized in the ward/ PICU, with consequent delay of the patient in the EC (with variable level of monitoring and management).

Deaths at the RCWMCH show a pattern similar to other SA childhood death data, although HIV deaths are declining, as is the situation countrywide.[70] For the 1999 to 2003 period, there were 1 978 deaths, 60% in children under a year of age; and HIV/ AIDS was responsible for 60% of infectious disease deaths (32% of all deaths). Some 7% were deaths prior to arrival at the hospital (largely home deaths), and another 9% in the EC of RCWMCH. The in-hospital deaths were split between PICU (37%) and medical wards (36%). Communicable diseases accounted for 59% of deaths (largely infectious diseases), non-communicable 29% (largely congenital abnormalities, as well as cerebral palsy and neoplasia) and trauma 8%.[70]

The 22-bed PICU at RCWMCH manages a mix of emergency patients (both trauma and medical which comprise around 60% of admissions), as well as elective surgical patients from various surgical disciplines.[71] PICU access is a scarce commodity in the province and hospital, such that the PICU has to make daily decisions on admission, based on resources, priority and expected outcome as described by Argent[71], but they note the increasing paediatric population in the province, with health services not keeping pace, has meant an increase in severity of illness and delay prior to PICU admission further compounding the pressure on PICU. Despite this, 2010 figures for the PICU show a mortality rate of 8.9%[71], comparable to international rates[2,72], although a direct comparison of mortality is not as meaningful as a comparison which takes severity into account such as using the Paediatric Index of Mortality 2 (PIM2) score.[2] The PIM2 score is a measure of predicted mortality for a patient, taking into account various admission physiological measures, including blood pressure, pupillary response, P_aO_2, FiO_2, base excess, and whether mechanically ventilated, elective or emergency admission, whether post-op or bypass, and whether relating to a list of higher risk diagnoses. The PIM2 score essentially provides an estimate of what the mortality for that sort of patient would have been in the reference ICU at the time that the score was set up. The actual mortality divided by the mean PIM2 score gives the standardized mortality ratio (which for RCWMCH PICU for 2010 was 0.68) [71], values less than one indicating that actual mortality is less than predicted (and a high level of care).

Despite the level of care offered by the RCWMCH PICU, there is an anecdotal feeling by clinicians there is that they can only do so much for children who frequently arrive at the door of PICU having had delayed and inadequate emergency care up to that point.

1.2.2 The Research Project

A collaborative research team from the University of Cape Town and the University of Oxford, UK, conducted a study to identify preventable failures in the medical care of critically ill children at all stages of the care pathway prior to intensive care admission or death in an EC.

We set out to conduct a study looking at the entire healthcare service for the sickest children in Cape Town. Children are a discrete, vulnerable group in society, and their healthcare is a good marker of the state of the health system in general; and from a practical point of view, critically ill children are ultimately referred to one of only two facilities in Cape Town (as opposed to adults who are managed across the system), with RCWMCH being the bigger of the two tertiary facilities managing children.

This need for this study had been previously identified by Professors Andrew Argent and Lee Wallis, and a month long pilot study conducted with the assistance of Dr Alison Ward of the Oxford University Department of Primary Health Care 4 years prior to this study. The pilot study showed that it was feasible (although laborious) to conduct such a study, recruiting patients admitted to RCWMCH PICU and retrospectively collecting and reviewing medical records from the acute episode (although the pilot was done without the caregiver interview element which would clearly add much needed insights to the pathway, care, timeline and caregiver's perceptions of the pathway). It was concluded that the study was viable, but would be labour intensive and require considerable development and resources to conduct, due to the multiple facilities and parties involved in each case, and the paper documentation of all health care records all kept in individual, geographically separate facilities, with the pathway between facilities sometimes difficult to elicit and only revealed by interview of the caregiver.

A protocol (***Appendix VI***) was put together, and a successful Welcome Trust grant application (WT091107MA) pushed the proposed study into reality. I was employed at this stage to develop and oversee the clinical review process, and assist with the co-ordination of this research project, as well as to write up the outcomes for publication and a PhD. The main findings of the study have been disseminated at various forums, such as oral and poster presentations, and reports as detailed in ***Appendix IV***.

A general literature review and detailed description of the methodology are followed by several discrete chapters, each containing: a literature review, the specific results, and pertinent discussion, followed by a final discussion which ties the whole project together and discusses the methods used and how they influenced the results. Following this there is a recommendation section giving some directed suggestions for how to implement and action some of the major findings of the study in this health system and how to further the techniques and methods developed in this and other settings.

1.3 Aims and Objectives

Research question

What is the process from first presentation to the health care system through to admission to PICU for critically ill and injured children and their caregivers in the health care system, and what can we learn from these issues to make recommendations for optimization of the acute care process?

Aims

The aim of this dissertation is to understand the existing systems and the barriers to paediatric critical care in the Cape Town metropol and thus to identify feasible interventions to improve the system.

Objectives

1. Develop a method to assess quality of care across a health system:
    1.1. develop consensus standards of paediatric emergency care to facilitate objective assessment of care across facility levels
    1.2. develop a list of modifiable factors, based on other sources, which will give meaningful outcomes to the study
    1.3. develop and implement an online data collection tool to collect data from a multi-step pathway to PICU for a sample of children and to enable an online, blinded expert clinical review.

2. Enrol a sample of critically ill and injured children over a year long period:
    2.1. identify emergency admissions to the RCWMCH PICU over a one year period, 1 November 2011 to 31 October 2012 and to enrol a sample of all those admitted in alternate weeks
    2.2. identify all paediatric deaths in ECs at RCWMCH and the surrounding health facilities over the year-long study period
    2.3. for each of these PICU admissions and EC deaths, to obtain detailed data on all aspects of their acute healthcare episode, from first presentation to PICU admission or death, by collection of all medical records and data from each facility and EMS transfer involved, as well from interview with the caregiver of the child.

3. Conduct an expert clinical review on each case to establish quality of care, assess standards of care, identify and grade modifiable factors and thus to seek preventable failures in the pathway to care.

2 LITERATURE REVIEW

2.1 LITERATURE SEARCH METHODOLOGY

An extensive literature search was undertaken at the beginning of the research period (2011), and was repeated at regular intervals throughout the intervening period until completion of the thesis. The last search was in December 2014.

Searching was completed using a combination of electronic medical databases, general electronic search engines, and medical library information. Search terms varied for different sections of the thesis, falling mainly into paediatric health systems, emergency and critical care articles, as well as those relating to confidential enquiries, child health, and standards of care.

Electronic medical databases searched include:

- Pre-Medline
- Medline (1966 – present)
- Embase (1974 – present)
- Cinahl
- British Nursing Index
- Cochrane library (all databases)

All retrieved records were assessed for relevancy.

The Google® and Google Scholar® search engines were searched using more general terms.

Attempts were made to identify relevant articles in the grey literature, through sources including:

- The System for Information on Grey Literature in Europe
- The National Technical Information Service (NTIS) Federal Research in Progress database
- Dissertation abstracts

Conference proceedings were searched where possible, through databases including:

- ISI web of science index of scientific and technical proceedings
- Conference papers index
- British library online catalogue

The National Research Register was also analysed.
The bibliographies of all papers retrieved were analysed for any other relevant articles. All relevant English language articles were retrieved.

2.2 CHILDHOOD MORTALITY AND MORBIDITY IN SOUTH AFRICA

This section describes the current international, and then SA and Western Cape childhood mortality and morbidity statistics, to show the present state of health systems and to try to identify where the issues amenable to interventions lie. There are various sources of data, many looking at different periods with an inevitable lag from collection to publication which adds to the complexity of interpretation.

2.2.1 Millennium Development Goals

The Millennium Development Goals (MDG), a set of global targets for improvement to reduce poverty around the world in 2000, include reducing child mortality as the fourth MDG.[73] Key indicators identified to measure this were the under-five mortality rate (U5MR) (number of children under five years old who die in a year per 1000 live births in the same year) and the infant mortality rate (IMR) (number deaths in children under a year of age per 1000 live births). The U5MR is thought to be an indicator of not only the health of a population, but also its socio-economic status.[74] The target was reduction by two thirds from 1990 to 2015. Already the WHO has had to accept that the world will not meet this target.[75] Although there is progress – worldwide figures show a reduction in U5MR from 87 in 1990 to 51 in 2011 (a 41% reduction), it will not be enough to meet the 2015 target.[76] The stumbling blocks are in LMIC, and in particular Sub-Saharan Africa where rates have gone from 178 (1990) to around 109 (2011): a 39% reduction but still unacceptably high relative to HIC numbers which are now in single figures as shown in Figure 2-1.[75,77] The United Nations response is that major "systematic action is required to target the main causes of child death (pneumonia, diarrhoea, malaria and under nutrition) and the most vulnerable children"[75]. There are disparities within regions and countries even in Sub-Saharan Africa who are likely to meet the targets, proving that it can be done.

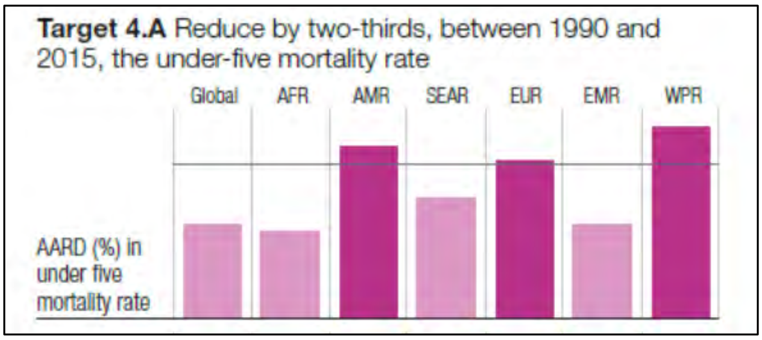
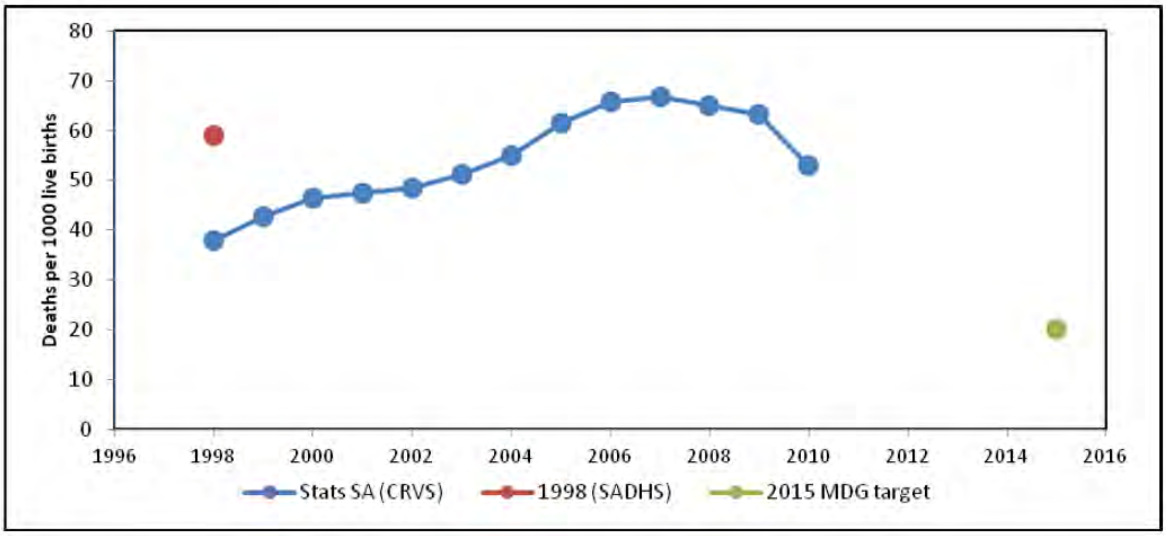


Figure 2-1 Global and WHO Regional progress towards the achievement of health related MDGs 5 (World Health Organization, 2013)[78]

(WHO World Health Statistics 2013) (AARD – average annual rate of decline; WHO Regions: AFR Africa; AMR Americas; SEAR South-East Asia; EUR European; EMR Eastern Mediterranean; WPR Western Pacific

SA in the previous decade showed an increase in U5MR contrary to MDG goals, from around 60 in 2000 to 68 in 2008.[79] These indicators were reflective of the peak of the HIV/ AIDS epidemic (accountable for 57% of U5MR in 2008), despite likely improvements in other aspects of childhood health. However there were many opportunities for avoiding deaths through better implementation of existing packages (such as PMTCT; IMCI and better postnatal care) and strategic prioritization, which did not negate the effect of HIV/AIDS.[79,80]

However more recent figures are perhaps hopeful. The SA MDG 2013 Country Report[74] is adamant that SA will meet the targets for U5MR and IMR by 2020 as shown in Figure 2-2, although finding key health related statistics and indicators for SA is a difficult task with some significant variations in reported figures between key national level publications.[74] Figures for SA U5MR vary across reputable sources: the most recent and likely show U5M at 42 and IMR at 30.[43]



Source: Demographic and Health Survey 1998, Department of Health; Mortality and Causes of Death, Mid-year Population Estimates, Statistics South Africa

Figure 2-2 Trends in under-five mortality rates in South Africa 1998 to 2011 and the 2015 MDG target (National Coordinating Committee for the Millennium Development Goals, 2013)[74]
(CRVS civil registration and vital systems); SADHS (South African Demographic and health Survey)

There is some optimism, although SA will not meet MDG targets. SA has made great strides in the last five years tackling the HIV/ AIDS epidemic, as well as other spheres of healthcare, but perhaps insufficiently in strengthening PHC and integrated services.[81] Future prospects are likely tied to the National Health Insurance (NHI) scheme which is envisioned to integrate the public and private healthcare sectors to reduce the inequities between the two and spread the health resources optimally.[80]

2.2.2 Child Gauge

The Children's Institute, University of Cape Town publishes an annual report "Child Gauge" that describes and monitors children's rights, services and key indicators in SA.[43] It was compiled from a variety of sources including census data, Department of Health data, and other publications and surveys to give perhaps the broadest picture of the health care of children in SA. The 2013 publication referred to 2011 data which were analogous to the data collected in the Pathways to Care (PTC) study. Relevant data identified from this publication (all for 2011 unless specified) includes the following:

i. The population of SA was estimated at 50 million people, of which 18.5 million (37%) were children (defined as < 18 years old). Children were equally distributed across ages so there were around 1 million children for each year of age. In the Western Cape the total population was around 5.5 million, with 1.8 million children (33%). Data show significant migration of people including children into the more urbanized provinces, including the Western Cape.

ii. There are significant inequalities between the provinces of SA, with the Western Cape consistently having the best picture for children living with both parents, least number of orphans, most employed parents, and fewest number of children living in poverty (31.8% vs 58% for SA).
iii. Indicators of child health (U5MR and IMR) are improving countrywide: U5MR decrease from 56 (2009) to 42 (2011) and IMR 40 (2009) to 30(2011), largely attributed to reduction in HIV-related deaths. Around 50% of childhood deaths remain HIV-related, with antenatal prevalence (public sector only) of HIV around 30% for the country and 18% for the Western Cape (increasing likely due to immigration from other provinces). HIV vertical transmission rates have declined due to successful PMTCT programs and are estimated to be 2.7%.
iv. Child Gauge looks at the number of children living far from their nearest health facility, defined as more than 30 minutes travel by any means to reach it, as this is thought to be a good indicator of access to care. In SA 24% of children meet this criteria, and in the Western Cape just 7.6%, the best in SA (worst KwaZulu Natal, 35%). They also allude to racial differences, with 27% of African children living far from their health facilities, with less than 10% in other population groups, and in means of transport, with only 7% of African children transported by private car versus 93% of white children.
v. Malnutrition is an important factor in child health, associated with greater risk of death as well as poor development and adult health. Around two thirds of SA children are underweight for age, with a third severely malnourished.
vi. In SA 53% of children live in urban areas, and 95% in the Western Cape, the highest in the country. Around 16% of the Western Cape's children live in informal housing (versus 10% in SA (likely reflective of recent immigration)) and 23% live in overcrowded households (> 2 people per room) (versus 21% for SA). Basic services for children in the Western Cape show provision of water on site to 95%, and basic sanitation for 94% of households.

The apartheid legacy has left persisting inequities in the Western Cape province, as for the rest of SA, with population groups divided by socio-economic status with gross disparities between population groups in every health indicator, including life expectancy, U5MR, IMR, *etc.*[82] Disparities between cultural or racial groups are far from unique to SA. Studies show disparities across sub-Saharan Africa in different ethnic groups, with inequitable socio-economic and consequent health status in almost every country.[83,84]]

2.2.3 SA Saving Children (Child Healthcare Problem Identification Programme (ChIP))

Collection and analysis of reliable data for deaths has been identified as key to identifying avoidable issues around the healthcare of the sickest individuals and the so called "confidential enquiry" models around the world have developed this technique.[52] In SA, although there is increasingly complete information on numbers and primary cause of death through death registration[85], further information is lacking from this system. Maternal mortality has been audited through a now legislated system, for some time[86] and this has been followed by auditing of childhood deaths in hospital through a voluntary system of individual health facilities collecting data on each death in their facility and central analysis and write up into annual reports, termed the Child Healthcare Problem Identification Programme (ChIP).[87] Available data from each inpatient childhood death are collected from medical records and assembled by an identified senior clinician in each facility. Those data are discussed at a morbidity and mortality meeting. A datasheet is completed for each death after discussion, which requires the identification of "modifiable factors" both prior to hospital arrival, in the EC, and in the ward which may have been linked/ causative to the death and/ or could be improved. These data are entered into an online database and collated nationally.

The "Saving Children 2010-2011"[88] report, published in 2013 covers the study period. The report highlights that there are better data collection than ever before, with an increasing number of participating facilities (149 hospitals), reviewing 4 758 deaths for the calendar years 2010 and 2011, albeit that this represents just 42% of health facilities in SA. The data overall showed an improvement in hospital care across all provinces, evidenced in a drop in the in hospital mortality rate from 4.2 (2009) to 3.0 (2011). This improvement may be due to interventions such as vaccinations and antenatal HIV prophylaxis, of note the reductions were due almost entirely to a reduction in infective causes, the biggest *Pneumocystis jiroveci* pneumonia (PCP), then meningitis but sepsis showed little improvement, and neonatal deaths and tuberculosis (TB) were still high. Around 60% of deaths were in infants (less than a year of age) (10% of these in neonates less than a month), an unchanging statistic over several years. Two thirds of children who died were underweight. The HIV prevalence in this group was just 21% HIV positive, a dramatic drop from prior 31% - likely due to antenatal antiretroviral prophylaxis (although coverage is incomplete). Only 10% of children were receiving ARVs at the time of death, although they were likely indicated in many more.

The commonest causes of death (where they featured as a diagnosis) were pneumonia (31%), gastro-enteritis/ hypovolaemic shock (26%), sepsis (22%), PCP/ pulmonary TB (PTB) (19%) and meningitis (10%). Nearly a third of deaths (30 %) occurred within 24 hrs (and almost 60% within 3 days) of admission to hospital, suggesting late presentation (as does the low weight for age in many presenting children), poor initial emergency care (especially poor initial assessment and insufficient recognition of severity). Half of cases were referred: 13% from a hospital and 30% from clinics.

ChIP identified modifiable factors in terms of:

1) RESPONSIBLE PERSON
   Clinical personnel 58.1%
   Administrator 13.5%
   Caregiver 28.4%
2) SITE
   Referring Facility and transit 4.5%
   Ward 27.0%
   EC 22.6%
   Clinic and Outpatients 16.2%
   Home 29.8%

Table 2-1 and Table 2-2 show the common modifiable factors countrywide. It is clear that emergency assessment and management is an issue, communication with referring institution, HIV management, access to PICU, as well as caregivers apparently not identifying or reacting to danger signs are prominently identified issues (although judgement of the caregiver's issues is largely subjective given the information available only from medical records).

Table 2-1 Common modifiable factors (by responsible person) identified in children who died (Stephen, CR, et al,2013)[88]

Modifiable factor: Clinical Personnel	*% of deaths*
Inadequate history at A&E	31
Inadequate notes on clinical care / assessment	29
Inadequate assessment for HIV at Outpatient Department (OPD)/Clinic	29
Blood glucose not monitors in child with danger signs	27
Modifiable factor: Administrator	
Lack of High care and Intensive Care Unit (ICU)	13.2
Inadequate number of doctors assigned to children's ward	7.5
Inadequate number of nurses assigned to children's ward	4.3
Primary care giver unemployed, no household breadwinner	3.9
Modifiable factor: Caregiver	
Caregiver delayed seeking care	23.7
Care giver did not recognise danger signs	21.2
Child not provided with adequate food at home.	12.6
Traditional remedy given	9.4

Table 2-2 Common modifiable factors (by place) in children who died (Stephen, CR, et al ,2013)[88]

Modifiable factor: Wards	*% of deaths*
Lack of high care /ICU facilities	6.6
Inadequate history taken in ward	4.8
Inadequate number of doctor	3.8
Insufficient notes on clinical care	3.5
Modifiable factor: A&E	
Inadequate history taken	8.1
Inadequate notes on clinical care	7.4
Blood glucose monitoring in child with danger signs	6.9
Inadequate investigations	6.0
Modifiable factor: Transit	
Severity of child's condition incorrectly assessed	13.0
Inadequate referral letter from referring facility	9.6
No or delayed referral to higher level	9.0
Inadequate notes on transit care	8.4
Modifiable factor: At Clinic	
Inadequate assessment for HIV	10.3
Child growth problem inadequately classifies	7.9
Delay in referral for sever weight loss m	6.7
Inadequate notes on clinical care	5.4
Modifiable factor: Home	
Care giver delays seeking help	22.6
Care giver did not recognise the danger signs	20.6
Child not provided with adequate food at home	12.0
Traditional remedy	9.0

Western Cape ChIP data show an in-hospital mortality rate dramatically lower than elsewhere in the country of 0.8%, as opposed to the national average of 3.0% (worst in Mpumalanga, 5.2%). In the Western Cape only 50% of children were underweight for age; HIV data showed 8% exposed and 11% infected. The causes of death were similar to countrywide figures, although sepsis was higher than gastro-enteritis – possibly due to an extensive strategy for gasto-enteritis management in the province. [89]

2.2.4 Other Data Sources

A Health Data Advisory and Coordination Committee (HDACC) was established to improve and link all data sources on health outcomes in SA and aims to provide central filtered information from all data sources.[90] The figures derived from this source give an U5MR of 56 (2009); IMR 40 (2009) and NMR 14, in keeping with other data presented.

SA has a rapid mortality surveillance system[77] which essentially tracks death records with a faster response time than other analysis of these data. Trends over the last decades showed a peak in natural causes of deaths around 2005-2007 both in adults and children due primarily to the AIDS epidemic, and since then a reduction in deaths due to improved management and prevention of AIDS.[77] Childhood deaths show significant seasonal changes as shown below in Figure 2-3. These summer diarrhoeal disease and winter pneumonia deaths are an ongoing cycle, but attenuating with reduction in AIDS.

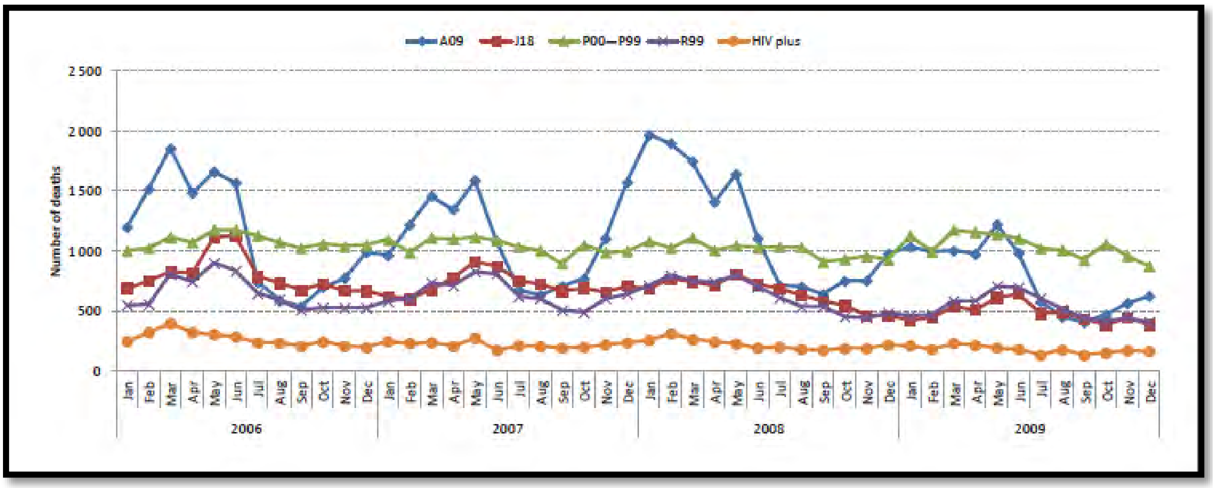


Figure 2-3 Number of child deaths under 5 years of age by selected causes of death (Bradshaw D, D. R. E., Laubscher R, 2012)[77]

A09 diarrhoeal disease; J18 pneumonia; P00-P99 perinatal deaths; R99 unknown cause; HIV plus HIV related deaths (limited by disclosure on death notification).

2.3 THE PATHWAY AND PROCESS OF CRITICAL CARE

To understand the issues and time intervals when a critically ill or injured child accesses health care it is useful to look at the elements of the pathway in obtaining emergency health care. A practical model of delay, developed originally to analyse obstetric delays, the "three-delay model"[91,92], has been applied to various settings and patient groups[93,94], including neonatal care[95] and paediatrics[96] and provides a useful structure and classification for each element of the initial critical care process.

Figure 2-4 shows the three phases of the model and some of the common factors which may play a role in each phase. The focus of this study is on the second and third elements, the care received once at the health facility (*i.e.* where and how they entered the health system and then documenting what happened within the health system), but it is hard to ignore the pathway prior to presentation as it gives some understanding of the difficulties and consequent delays in arriving at an appropriate facility. In LMIC in particular, lack of knowledge and poor recognition of the deteriorating, ill child and neonate has been shown to be of great importance. [97,98]

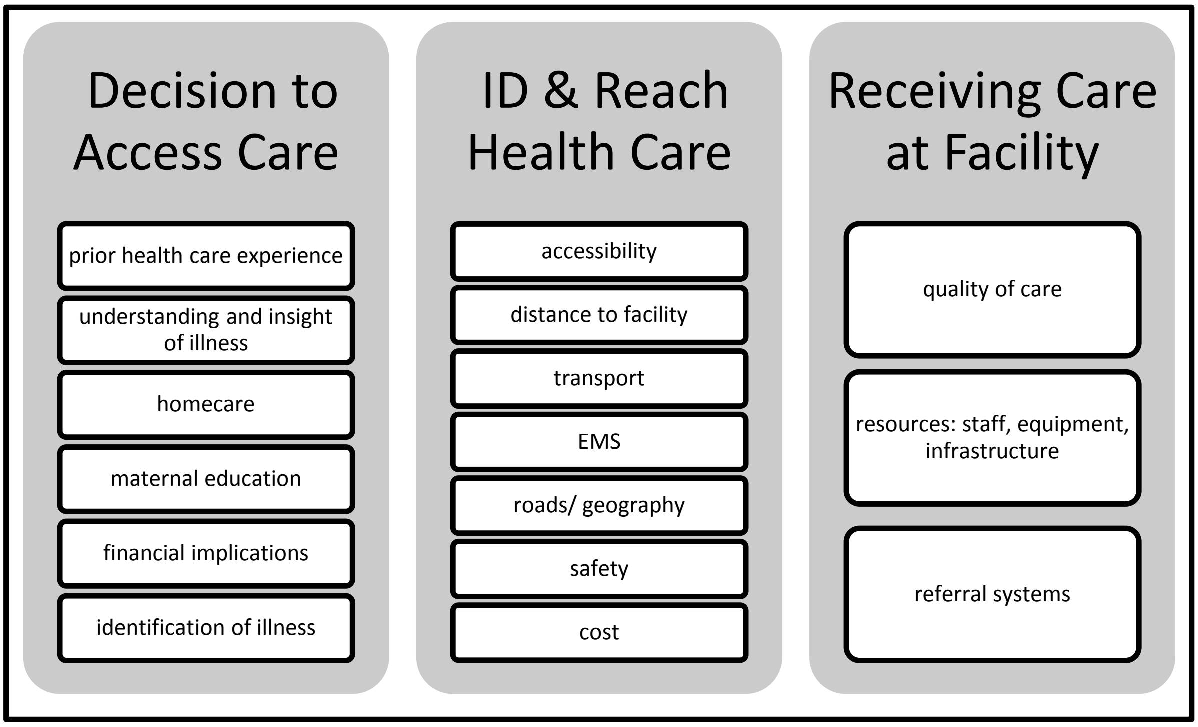


Figure 2-4 Summary of three-delay model of delay to care

2.3.1 Access to HealthCare

There is a vast field and much literature focusing on why, -when and how people access healthcare services, and more specifically looking at caregivers of children and their access decisions.[95,99-106]. Although it will usually be a complex decision and behaviour when, where and from whom a caregiver seeks healthcare for an ill child (as shown in Figure 2-5), and tied to the context and available resources, each element and specifically examples from LMIC will be discussed separately.

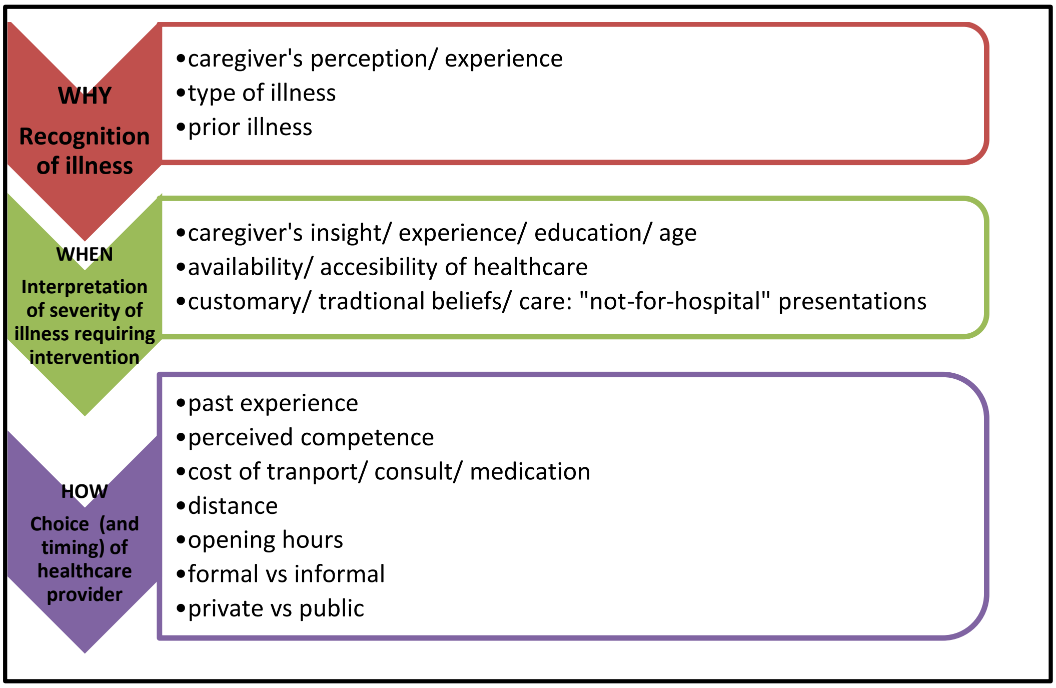


Figure 2-5 Factors influencing access to care decisions

There is a body of research which has looked at illness recognition and at health seeking behaviour by caregivers of children in various settings.[107-109] Methodologies vary, most using either household survey questionnaires, or looking at some subset of health facility patients. Although it is difficult to directly relate some of this research to the SA context where public health services are relatively good and available there is much to learn from these studies, some conducted in rapidly expanding urban areas with a recently urbanized population not unlike some population groups in Cape Town. The common issues identified are distance to health facilities, cost of services (and household income), perception of the quality of care, and linked to the last, prior experiences with the health systems and facilities.

Two studies from Ghana looked at illness recognition, the decision to, and the factors around accessing care.[110,111]. Hill[110] conducted qualitative interviews with 322 caregivers in a rural area, and showed that there was poor recognition by caregivers of what the IMCI program would identify as “danger signs” in many cases. Even when recognized as severe, only half of the patients were taken to a health facility.[110] Some dangerous symptoms were generally well identified, including convulsions, measles and dysentery, while symptoms around dehydration, respiratory distress and malnutrition were often missed or underestimated for severity. Reasons for not seeking health care, even in children recognized as severely ill by caregivers, included illnesses which were “not for hospital” (33%), illness that could be cured at home or by a healer (33%) and lack of money to seek health care (33%). The authors suggest that interventions to improve this state should look at the complex issues around symptom recognition within the context of traditional beliefs, as well as access to care, while Buor[111] identified distance and travel time as the most important factors influencing utilization of health services in adults, with income, costs and education secondary factors.

Children living in urban slums is an unfortunate reality for all LMIC cities – in fact a report says “one in three people worldwide will live in an urban informal settlement in the next two decades”[112]. In Nairobi[113], 60% of the population live in such slums, with far higher infant and child mortality than elsewhere in Kenya.

Major determinants of when a mother seeks healthcare were: maternal recognition of signs and symptoms, health beliefs (some illnesses are "not-for-hospital"), cost and lack of access. They conducted a household survey (15 174 households with 3015 under-5 children), specifically asking about children with recent illness or injury. They found health seeking was strongly associated for children with perceived severe illness (although of questionable reliability); younger mothers (older mothers perhaps have more children, are unable to prioritize, rely on past experience and customs (perhaps traditional therapies)); and for those with higher household income/ expenditure; as well as lesser associations for those with diarrhoea, infants, and mother's with more education.

In remote and rural areas, most people visit traditional medical practitioners; while in urban areas people tend to bypass primary level health care facilities seeking treatment at tertiary level health facilities[114]. Important factors which determine health service provider selection (in adults) included: education level (more educated patients seek health care rather than self-care or traditional medicine), perceived quality of health service (resulting in direct presentation at secondary and tertiary facilities rather than at PHC centres), travel time to health facility, cost of care, and perceived severity of illness (more likely to seek higher level care for severe illness).[114] There were similar findings in urban Burkina Faso[115] - most of the population sought formal care sources for management of "severe" conditions (as opposed to informal care being traditional healers and self-treatment for less severe conditions), with around 20% of these choosing the private sector (especially those with more education and employment). Choice of which provider to access was made primarily based on closer proximity, perceived better provider competence and less expensive services.

There are inequalities and access difficulties in urban Cape Town – the public sector serves largely the poorer, predominantly black African and mixed race ("coloured") population with high unemployment rates.[61] This population has a high prevalence of infectious diseases and trauma – largely relating to poverty and lifestyle, requiring emergency access to healthcare. Yet after hours there is limited PHC, accessible only by private transport. Public transport is aimed at commuters and not necessarily useful for health care access – except for the larger hospitals which may be more accessible by public transport, but bypassing primary care is discouraged and patients may be refused at larger hospitals unless the health practitioners share the same initial perception of acuity as the caregivers.[61]

Separating the issues into demand and supply provides an alternate way of looking at access to care (Figure 2-6).[116] A systematic review of LMIC revealed that the predominant demand issues in LMIC are education, actual cost of accessing healthcare (including transport, missed employment and health care costs), and cultural barriers (including gender, religious and traditional decision making). They suggest interventions should be focused as much on the demand side (*i.e.* the barriers within communities) rather than only the supply side (being availability, cost and quality of health care).

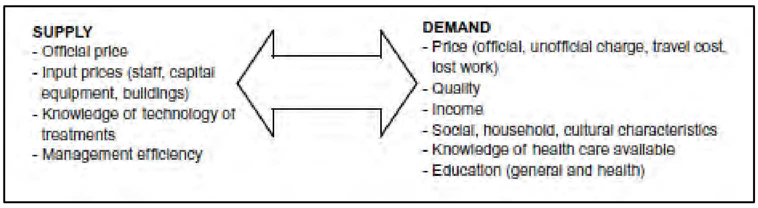


Figure 2-6 Supply and demand barriers to health care utilization (Ensor, T. and S. Cooper,2004)[116]

2.3.1.1 *Emergency Centre Access*

EC access to care in the United States (US) has evolved in the last 20 years: initially the issue was many "inappropriate" or "non-urgent" EC visits (although the precise definition has always been grey and varies between studies) and there were efforts to reduce these numbers (and costs) through triage (although primarily developed to prioritize the need for care rather than assess the necessity for care) and patient education.[107] The next era was concern around delayed access to care and not denying EC access with the EC seen as a safety net. And the more recent phenomenon is EC overcrowding with long waiting times to be seen creating their own "internal" access issues, described as "overcrowding in the ED: an international symptom of health care system failure".[117]

The UK National Health Service (NHS), often lauded as a model for socialist health care, is currently under pressure, some of which relates to access to care, with perceived overuse of expensive and often inappropriate emergency services, while general practice (GP) and PHC services are underutilized and/or under resourced.[118,119]

EC's are defined by two central concepts: 24 hour access, and care to all who seek it – through the professional ethics of those running them, and these tenets are obligated by law in many countries including SA.[107]. The US Committee on Paediatric Emergency Medicine[106] in 2007 published recommendations, along with a list of problems, for children in accessing emergency care. Yamamoto[106] provides two key statements below relating to primary first access to healthcare, and to access to critical care resources:

- "Improve prompt and appropriate access to pediatric emergency medical care for all children regardless of socioeconomic status, ethnic origin, immigration status, type of insurance, location, or health status."[106]
- "Encourage all EDs to establish transfer agreements with facilities with higher levels of pediatric care to ensure timely access to pediatric emergency and subspecialty tertiary care for critically ill and injured children."[106]

Most SA hospitals suffer from an overload of undifferentiated patients, many of whom could be managed more efficiently and effectively in a PHC facility.[120] A study in George[121] (a medium sized town on the eastern border of the Western Cape) looked at reasons why patients present directly to a secondary hospital rather than to a PHC facility. Over a month-long period, they looked at only patients triaged green (SATS) (adult and children) to see why they had bypassed primary care (89% were self-referred) and reasons were given as:

- clinic medicines not helping (28%)
- perception that hospital treatment superior (24%)
- lack of after-hours PHC service (22%)
- PHC waiting times long (14%)
- "special tests" available at hospital (12%)

Although this study may not be entirely representative of other urban SA settings, as there are no other after hours emergency facility in the town, it does provide some SA data on bypassing PHC.

2.3.1.2 *Which Hospital to Access*

Healthcare in SA, as in many other countries is divided by financial means into the public sector, government provided health care for the destitute and poor, and private sector services for those able to afford them or provided by employers with medical aid. There is widespread variation in the quality of care for both sectors. Patient perceptions seem to be that there is better care in the private sector, despite the fact that in many instances care has been shown to be worse in the private sector despite the better waiting times and hospitality.[122] Of interest, patient perception of quality of care varies between studies[122], although separating the perceived competency of the practitioner from the "hospitality" and receiving desired testing/ medications is difficult.[122] Outcome from public sector healthcare appeared to be better than in private (and especially so for TB, HIV and STDS), and the cost efficiency was worse for the private sector almost universally. A study across 24 LMIC private sector practitioners demonstrated that childhood diarrhoea management was more often inappropriate than in the public sector, for example few private practitioners were providing appropriate oral rehydration solution, and many were prescribing unnecessary drugs.[123]

2.3.1.3 *Ambulance (EMS) as first access point for children*

Anecdotal SA data suggests that EMS is seldom the first point of access for ill children and particularly not for younger children and infants (although trauma is seemingly seen as an ambulance issue). The international experience (largely from HIC as EMS systems are so undeveloped in LMIC countries) would seem to be similar, with children less often using EMS services. In an urban New Mexico hospital (US)[124] fewer children were brought in by EMS than adults irrespective of severity: for all patients the ratio was child: adult 7%: 19% and for those requiring critical care 66%: 87%. Another US study[125] showed only 13% of high acuity children utilized EMS. Generally in the US there is concern over "overutilization" of EMS by children with "inappropriate" EMS transfers, likely due to convenient and low cost/ subsidized EMS systems.[126] Various plans to reduce "inappropriate" EMS transfers include EMS triage, educational programs, alternative modes of transport *etc.*

Possible reasons for the underutilization of EMS by critically ill children in the US settings, all of which may be pertinent to our setting include:[124,127]

1) Caregiver lacks confidence in EMS capabilities
2) PHC advice to use private transport
3) community lacks understanding about paediatrics EMS services/ need for paediatric EMS transport
4) caregiver lacks understanding/ ability to differentiate care at various levels/ sites
5) difficulty determining the necessity/ appropriateness for EMS
6) children are easily taken by car (mobility/ assistance level) (although lack of ownership of car should mean more use of EMS.)

African and SA data are lacking on the relative utilization of EMS by children and adults. The only local information found is from a 2008 study[128] at a Cape Town regional hospital (where just 10% of EC patients were children). Unpublished data from this study shows that a similar rate of children (37%) and adults (39%) arrived by ambulance. And looking at severity, 59% of the children arriving by ambulance had a SATS score of red or orange, as opposed to 45% of adults. So it remains unclear whether SA children utilize EMS more or less than adults.

The other issue is whether EMS practitioners are comfortable and proficient at dealing with critically ill children. Several US studies[129-132] suggest that pre-hospital encounters with critically ill and injured children in the US are so uncommon that practitioners do not retain skills (such as paediatric intubation skills) and are not confident with paediatric resuscitation.[133,134] There is little evidence around the situation in LMIC or even SA. Although SA EMS crews are more likely to deal with critically ill and injured children, and ALS practitioners are trained to a high level, including paediatric management, it is unclear whether their training or experience provides the expertise and confidence required in paediatric resuscitation.[135,136]

2.3.2 Health Facility Care of the Critically Ill Child

In many health systems, including in SA, most critically ill children will present initially to a non-specialist health facility. A Canadian study[99] looked at how a generalist or a community paediatrician in a lower resourced setting (in terms of staff, equipment, and recent training) struggled to offer high quality care to critically ill children – having identified such a child, they attempt to stabilize the child, while dealing with a receiving hospital and ensuring an appropriate ICU bed, and finally organizing appropriate transport. The experience was stressful (allegedly more so than managing a cardiac arrest) and could immobilize the entire department (perhaps leading to a greater urgency to refer and send the patient on). They identified issues that frequently arise, and were anxiety causing, and where they would like more training being: respiratory, trauma and cardiac presentations, and the very young patient. Specific identified “barriers” to care were identified as follows:

- “situational staffing issues and specialised staff availability
- physical layout of the hospital
- lack of paediatric specific acute care knowledge and awareness of guidelines
- lack of experience and paediatric technical skills due to infrequent exposure to paediatric acute care
- lack of proper equipment
- lack of teamwork and communication”[99]

All of these findings likely relate well to SA settings, especially at clinics and CHC level (even though most CHCs would see a higher frequency of critically ill children in our setting (each Canadian facility saw only around one critically ill child a month). The authors conclude that although some of the issues are primarily system issues, education of practitioners is vital and needs to be looked at beyond short courses in resuscitation, with the importance of building local relationships between referring and receiving facilities for advice, knowledge exchange and mentorship; and developing better knowledge translation strategies (for example dissemination of guidelines, followed by simulation training).[99]

Several groups and papers have looked at source of PICU patients and how this relates to their acuity.[72,137,138] Findings are somewhat conflicting, perhaps related to the context and local health system, but it seems clear that patients from the hospital EC admitted to PICU are sicker (higher PIM2, more ventilator and inotrope use), likely explained in that they have not yet been fully stabilized with all appropriate care and can improve. The mortality and length of stay of those admitted from hospital wards and other PICU’s is higher (these patients may be deteriorating on full appropriate therapy with relatively normal physiology and thus lower PIM2 scores, although the outcome is no better).

Many international health systems make extensive use of paediatric retrieval teams, where a high level team (often PICU staff) from the receiving hospital of a critically ill or injured child, go out to stabilize and collect such an identified child at a lower level facility.[139,140] There is a some evidence for the effectiveness of such teams,[141,142] while others suggest that parallel improvements in intensive care are more likely to responsible.[143] Cape Town data[144], although somewhat dated but with recent data showing little change (personal communication C. Demetriades, 2014) and experience suggests that given the high adverse events in transferring critically ill children by non-specialists, retrieval teams are perhaps indicated or at least further paediatric specific training for providers of such transfers, although this would have to be carefully balanced with other service provisions in a resource constrained environment.[145,146]

2.3.2.1 *Triage*

Triage was first developed to prioritize care of the injured on the battlefield in a conflict situation[147], developed into mass casualty prioritization ("triage sieve", *etc.*) but since the development of the speciality of EM it has been extensively modified and researched in different contexts (including less resourced settings.[148,149] Molyneaux[150] in Malawi, provide convincing evidence that triage of children in a LMIC setting can be implemented and is effective in prioritizing and allocating EC resources appropriately.

An SA group in the early 2000's, developed a triage system based on the Modified Early Warning Score (MEWS)[34], initially known as the Cape Triage Score[151] and rapidly becoming the South African Triage Score (SATS) which has been validated in various settings.[68,152,153] The SATS is now well recognized, and its use is mandated in ECs in the Western Cape. Although SATS has always had a paediatric tool, it has recently been further modified to add a specific paediatric element (and to make it more commensal to the ETAT approach (see below)) known as the Paediatric South African Triage Scale Assessment and Treatment (P-SATSAT).[154]

2.3.2.2 *Paediatric Emergency Medicine*

Internationally in well-resourced settings, paediatric emergency care has developed rapidly in the last two decades to being a sub-speciality on its right, with specific training, guidelines and protocols that have translated to improved quality of care and better outcomes, at least in tertiary hospitals where such specialists are present.[31,51] While these improvements are commendable, paediatric critical illness is a rare event in most well-resourced settings (and this is one of the limiting factors to improvement where such skills are uncommonly used[99]); as opposed to LMIC where the burden of childhood disease lies. Several well-known LMIC paediatric researchers[13,155-158] have described the lack of quality paediatric emergency care in various less resourced settings which is undisputed. Yet there are many examples of systems and facilities such as that in Malawi where system wide implementation of paediatric emergency care has proven to be feasible and worthwhile.[153,159]

2.3.2.3 *Paediatric Critical Care*

Shann[160] and Kissoon[161] describe the indisputable global inequities in childhood mortality, and the overwhelming burden in the lower resourced countries. But the way forward is not clear or uniform; in the well-resourced setting, critical care is an assumed right and necessity for the minority of the population that is severely ill, most commonly through non-infectious illness and occasionally trauma. Contrasting this, in LMIC, childhood critical illness and injury are common and often preventable, yet resources are lacking to provide critical care as health budgets in LMIC aim at PHC and prevention of critical illness and injury. These authors describe the spectrum of health services for children (Figure 2-7) and try to rationalize how critical care can and should be provided in resource constrained settings.

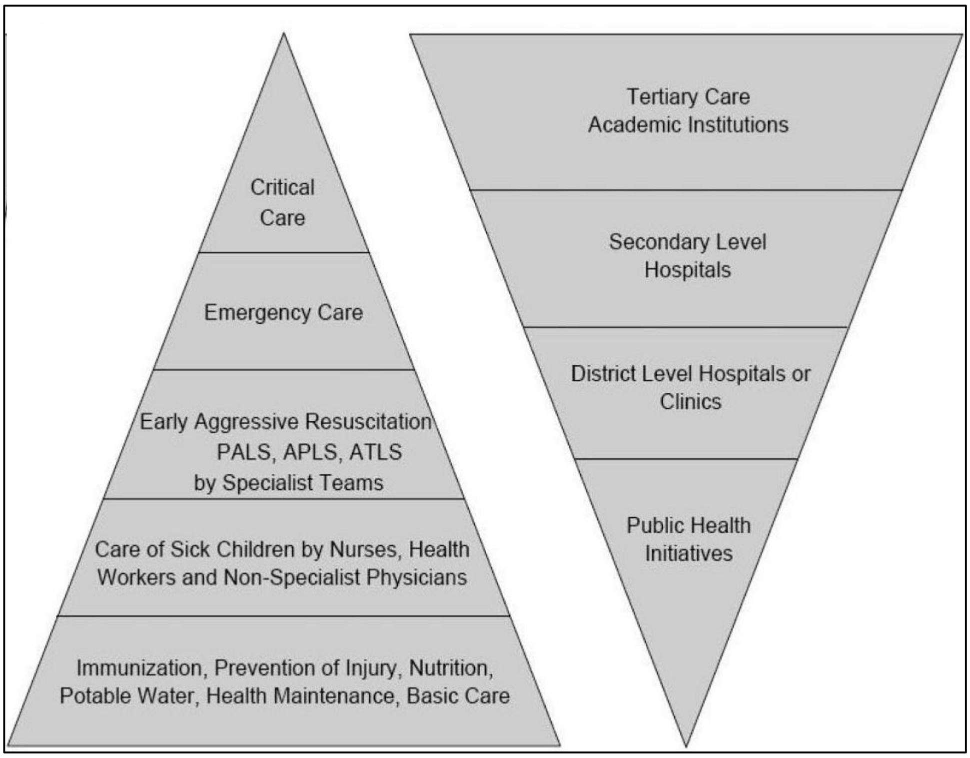


Figure 2-7 Spectrum of health services for children (Kissoon, N., et al. ,2009)[161]
ATLS, Advanced Trauma Life Support; *PALS*, Pediatric Advanced Life Support; *APLS*, Advanced Pediatric Life Support

Several authors have attempted to unravel the prioritization of critical care and intensive care for LMIC. Firstly critical care has to be defined –critical care extends from first accessing healthcare, through triage, hospital management and ultimately intensive care unit admission for a patient with an immediate life threatening illness or injury.[4,162,163] Intensive care is a highly resourced and equipped ward, usually in a referral hospital where patients are typically able to be ventilated, and have invasive monitoring and attention. Shann[164] defines what seem to be acceptable boundaries for which countries can ethically divert public funding away from preventative and PHC to intensive care – and he uses countries with an U5MR of >30 as clearly not able to support an ICU, 20-30 as perhaps in selected cases, and under 20 representing well developed health care systems where ICU is an integral part of healthcare. There seems to be a fair rationale for these numbers. Paediatric mortality in lower resourced settings is predominantly (>70%) due to infectious causes, and the majority of these are preventable, either by preventing the illness/ injury, or by better early care.[15] In such settings, diverting resources away from prevention, PHC and district hospital care is probably unethical – more lives will be saved by the former, rather than setting up and running extremely resource-hungry intensive care units.[165]. However, developing other elements of the critical care chain, according to the context of healthcare in each setting, is likely to improve mortality, and in many settings it may be simple elements such as first responder care, triage, EMS, oxygen, and antibiotics.[155,166] SA had an U5MR of 42 in 2011,[77] with the Western Cape substantially lower at 27-29 (2010 data[167], varies depending on sources). SA presents a mixed picture, with high levels of inequity, making the assessment even harder, but it is undeniable that in urban areas SA can and does support viable PICU services. There is another level of complexity, in that many countries (even relatively well-off LMIC such as Brazil and India) there are intensive care services regardless of the state of the countries health and one then has to debate the ethical issues of denying PICU access to some children and not others across the world.

2.4 QUALITY OF CARE IN PAEDIATRIC HEALTHCARE

Assessment of medical errors became a topical issue in the last two decade in the US, with various publications beginning to attribute a proportion of hospital deaths to poor medical care.[168-170]. A controversial publication[171] implied that medical error "kills 44 000 to 98 000 people a year in US hospitals". Much debate raged about methods and extrapolation to the general population, likely the in- hospital population is at high risk of death regardless and blaming it all on medical error is unfair, but the uproar was nevertheless helpful in instigating the patient safety revolution and campaign – with at least awareness as an outcome, although it is difficult to show specifically how it has improved systems.

This "patient safety" revolution (particularly the US), did compel many health facilities to institute patient safety initiatives and consequent audit and research of the incidence and type of adverse events at a spectrum of institutions. For example Dunn[172] looked for adverse events (defined as "unintended injury or complication which results in disability, death, or prolonged hospital stay and is caused by healthcare management rather than the disease process" in children who died or were admitted as emergencies to PICU (by record review and where necessary interview with involved clinicians). Although some of the adverse event literature shares elements with the confidential enquiry type approach (record review, blameless investigation of cases), it is distinct in looking beyond the disease process and modifiable factors in the management that would avoid severity/ PICU admission/ death, but rather looking at adverse events caused by error which are clearly linked to an adverse outcome – such as surgical/ anaesthetic procedural events; diagnostic events (delayed or incorrect diagnosis); therapeutic events (incorrect therapy/ delay in therapy); drug/ fluid (incorrect administration); or a system issue (due to hospital processes).

A patient safety audit of 47 PICU deaths[173] (over a year), identified adverse events (as defined above), as well as "critical incidents": "undesirable event in healthcare management which could have led to harm or did lead to harm of the patient but did not contribute to the patient's death" (alternatively known as "near miss" events)[174]. Their findings seemed to be closer to those of the confidential enquiries – they found that most adverse events and critical incidents occurred prior to PICU admission and were largely failures in diagnosis, assessment and management of critical illness. Terminology varies - "suboptimal care"[175] is another term describing essentially avoidable or preventable issues in the care of hospital patients as McQuillan[30] first used it in 1998.

Having identified that there are issues with the care and safety of critically ill patients – and this is clear in HIC, so doubtless true in LMIC, it becomes important to measure quality of care to quantify the issues and qualify exactly where and why they occur to target improvement interventions. Monitoring quality of care within a single institution (or even a single ward or unit of an institution) is a challenge, but within an entire health system becomes very complex and difficult and opens up the field of how to assess quality of care – which many authors are clear is an international research priority.[176-178] A good deal of research has focused on quality of care in adults (for example heart disease),[179] but there is a lack of focus and research on paediatric specific quality of care.[180-182]. The current evidence is that formulation of clear guidelines and protocols and then translating these into standards of care, and then using these to objectively measure adherence to standards – *i.e.* performance measures/ indicators is a powerful process to implementing change and improvement across health systems.

There is evidence of successful interventions on specific identified aspects of paediatric critical care that have been shown to improve outcome (below); although despite the clear evidence for many of these interventions in studies, and perhaps in some single institutions, it is also clear show just how hard it is to show improvement even in a specific element of the care of a well identified group of patients at a specific level – and thus how much more difficult it may prove to be to improve care across an entire health system.[26] Some examples of proven interventions are described below.

Septic shock: there is evidence in both adults and children for the effectiveness of specific care pathways or bundles of care and timing of these interventions (especially time to antibiotics)[23,24,183,184] . Yet implementing these bundles is not always easy - specific improvements may be clear, yet compliance within a system and sustainability, as well as collecting the data to prove the interventions can be challenging – in settings as diverse as Australia[22], Spain[185],US[22,25,33], UK[186-188]. Recent evidence from two large multicentre studies[189,190] disputes the effect on outcome of one of the established bundles of care – early goal directed therapy[17] and there is clearly more research to be done in these areas. If nothing else, this research area has drawn attention to the details and parameters of resuscitation for sepsis which has surely improved care.

Management for meningococcal sepsis, especially time sensitive, has been shown to improve outcome, but with an extremely resource intensive program.[191] Some authors question the feasibility of the full sepsis guidelines in Africa at all: blaming lack of resources (equipment, drugs and hospital beds); and suggest they need to be modified and feasible yet meaningful elements selected for resource poor settings[7], and system wide application.[192]

Trauma: although long a dogma of the “golden hour” for trauma interventions, with some good evidence to support this,[18] many systems struggle to achieve this, even in well-resourced settings.[193,194]

2.5 THE CONFIDENTIAL ENQUIRY AND OTHER LONGITUDINAL STUDY METHODOLOGIES

2.5.1 UK Style Confidential Enquiry – history, development, current report

Confidential enquiries, initially developed as local audits of maternal deaths as far back as the 1920s, have been conducted formally in the UK on maternal deaths known as CEMD (the Confidential Enquiry into Maternal Deaths) since 1952 – the world's longest running clinical audit.[195] Their objectives were clear: "to assess the main causes of maternal deaths and, through the identification of avoidable causes, to reduce maternal morbidity and mortality by recommending improvements in clinical care and service provision; it also indicated directions for future research and audit"[195]. In 1992 the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) was established to extend CEMD to early childhood deaths – defined as post 20 weeks conception to one year of age. And finally in 2003 CEMD and CESDI were combined into the Confidential Enquiry into Maternal and Child Health (CEMACH), including childhood deaths to age 16 years, with the inclusion of morbidity as well as mortality.[53] These reports, presented with clinical vignettes, as well as other parallel confidential enquiries, are thought to have had important implications for healthcare and to have improved practice in the UK – specific entities highlighted by the reports and likely beneficiaries include post-partum haemorrhage, obstetric anaesthesia, antenatal record keeping and planning, foetal monitoring, perioperative care, and sudden infant death prevention (although there is no "hard" evidence for their impact – impossible to separate or study apart from general improvements in health care over time).[195-197] Papworth[198] in 2004 (so prior to the amalgamated CEMACH reports) goes as far as to say that confidential enquiries "..are leading examples of how the healthcare professions can review their own work and bring about dramatic improvements.."[198].

The central philosophies of the confidential enquiry are confidentiality, names of individuals and institutions are removed thus avoiding any blame; clinicians rather than managers or politicians conduct the review and apply "clinical common sense" in their review; pattern recognition through review and analysis of many cases; practical recommendations which can be implemented; and dissemination of the findings to all role-players who can improve patient care.[196] There are alternatives to the confidential enquiry for investigating maternal deaths – but none that have yet proven themselves: public enquiry – which is long and expensive without a clear record of improving care; medico-legal inquest, litigation and prosecution – all of which aim to identify cause and blame on individual/ institution; hospital based enquiries which offer very local contextual findings of varying quality; and clinical governance and compliance with standards of care which may offer some value.

The current procedure used in the CEMACH is notification and identification of eligible deaths by institutions and regional CEMACH managers, followed by establishment of an enquiry panel for each case, comprising clinicians from every relevant speciality to the case, but independent from the hospital and case concerned. The enquiry panel, using anonymized case records, develops a review and these enquiries are analyses (using qualitative as well as quantitative techniques) and collated into reports.

2.5.2 CEMACH 2008 Pilot Study

The first CEMACH report on childhood deaths was published as a pilot study in 2008 to evaluate the feasibility and usefulness of this approach in a sample of geographic regions of the UK.[53,199] Key findings are summarized:

1) Confidential enquiries into childhood mortality and morbidity are feasible.

2) There were many examples of good practice.
3) Difficulty in recognizing serious illness in children, especially by non-paediatricians.
4) Failure to follow up as planned was a concern prior to many deaths.
5) Palliative care to children not optimal.
6) Need for further epidemiological review of childhood deaths.
7) Frequency of children with complex and long standing illness and inadequacy of death certificate information on these deaths.
8) Role of primary care is key to improving care and paediatric skills in general practice are vital.

Key concepts from the methodology used in the CEMACH 2008 Pilot study include:[53]

- Inclusion of deaths children aged 28 days to 17 years.
- Ascertainment of death through multiple sources: notification by health facilities, police, coroners, health and allied health practitioners and correlation to media reports.
- Collection of core data for all selected deaths: demographics, medical history, social, circumstances around death, processing of death (based on the Arizona Child Facility Review[200] data collection tool – see below).
- Random selection of cases for panel review (sampled from age groups and geographic regions).
- Collection of records for selected cases: copies of all relevant original medical, social, and educational records.
- Convening of multidisciplinary panels in each region including: hospital paediatrician, community paediatrician, pathologist, general practitioner, nursing, and two non-medical representatives (where relevant additionally: neonatologist, school nurse, surgeon, intensivist, and/or sub-speciality paediatricians *etc.*).
- Review of anonymized records by a panel from another geographical region at a panel meeting. Following discussion and consensus, use of standardized reporting tool to describe the case, contributory factors, and avoidable factors.
- Data analysis using predominantly qualitative approach.
- Reporting of cases where there was grave concern through CEMACH clinical director to the medical director of the involved health trust.

Of importance to the CEMACH report, and to this study which used the CEMACH methodology loosely as a developmental framework, definitions and gradings for the concept of avoidability were establishes as per Table 2-3.

Table 2-3 Confidential Enquiry into Maternal and Child Health (CEMACH) definitions for avoidable factors in childhood deaths (Pearson, G. A., 2008)[53]

1) Avoidable
a) Where there were identifiable failures in the child's direct care by any agency, including parents, with direct responsibility for the child
b) Where there were latent, organisational or other indirect failure(s) within one or more agency, including parents, with direct or indirect responsibility for the child
c) Where there was a failure of design, dilapidation of barriers, or inadequate maintenance by agencies with responsibility for public safety (e.g. rail maintenance leading to Hatfield rail disaster).
2) Potentially avoidable
a) At a higher level than the agencies with direct or indirect responsibility for the child (e.g. political violence, war, terrorism, crime, and if the child is the victim of homicide)
b) Where no agency, including parents, was involved directly or indirectly with the child
c) Where intrinsic factors (e.g. an acquired disease with a known high mortality such as meningococcaemia) were the principal factors leading to the death
d) Where there were potentially modifiable factors extrinsic to the child
e) Where the causal pathway leading to the death could reasonably be traced back to antepartum or intrapartum obstetric events.
3) Unavoidable
a) Death caused by unmodifiable factors extrinsic to the child (e.g. lightning strike, earthquake)
b) Death due to undiagnosed, asymptomatic conditions presenting with a lethal event (e.g. hypertrophic obstructive cardiomyopathy)
c) Planned palliation for unpreventable, incurable disease or anomaly (e.g. Leigh's disease).

The limitations of the CEMACH Pilot 2008 were well defined, and a challenge to balance and overcome in future studies. The data relied on documentation entirely; it was costly and time consuming and unlikely sustainable unless well justified to improve care; reviewers had retrospective information not always available to practitioners at the time; there was little or no information on local context (organisational structures, staffing, local guidelines/ practice, *etc.*) known to reviewers; the panel's conclusions were somewhat subjective and not necessarily repeatable; the report generalized a lot of information thus losing individual stories and issues; and cases were not compared to case controlled cases of survivors to look for differences in care.

The 2006 CEMACH study[53] identified 957 cases. Sixty-six percent of deaths were in hospital: PICU 33% (of which 117(62%) died following withdrawal or limitation of treatment); EC 27% (of which 78 (51%) were actually certified dead on arrival (DOA) so debatable whether they were actually hospital deaths); paediatric ward 18%; and neonatal ICU 10%. Deaths were classified as either non-natural (24%) including motor vehicle accidents (MVA), suicide, drowning, falls, fire, homicide, poisoning, substance abuse, and other; natural deaths (66%) including infectious causes (29% of natural deaths); and sudden unexpected deaths in infancy (10%). A high proportion of children (77%) had either a pre-existing disease, congenital abnormality, or cerebral palsy.

Of the cases selected for panel review (126 out of 957), avoidable factors were found in 26% of cases, and potentially avoidable in a further 43%. Discussion and commentary on the findings focus on the key findings, many with major implications for EM – inadequate triage and prioritization, failure to take an adequate history, failure to recognize and manage a seriously ill child, communication with parents, and inadequate senior clinician support. Suggested solutions include increased undergraduate paediatric emergency training and exposure, paediatric EM training for paediatric and EM trainees, and training and development of paediatric EM sub-specialists to work in high burden centres; and the development and application of standards for paediatric emergency care.

2.5.3 Other UK Confidential Enquiry literature

Harnden[201] performed a further analysis of the CEMACH 2008 data – two primary care physicians performed an independent review of the PHC elements of 168 of the CEMACH cases. They were able to confirm the main study findings, and further highlight primary care issues – avoidable factors were found in 20% of PHC cases – the commonest being failure to recognize and manage severe infection, as well as to highlight good practice . Of note the author's mention specific limitations of the study - interviews with parents were not part of the process, and that timelines were difficult to capture due to poor documentation. Many other disciplines and specialities (especially in the UK) jumped on the successes of the confidential enquiry – looking at entities as diverse as sudden infant death syndrome[202], peri-operative deaths[203], and asthma deaths[204]. Some studies incorporated interview with relatives and caregivers for additional information.

Since the landmark 2008 "Why Children Die" report[53], CEMACH has gone through a succession of transitions, in 2009 it became Centre for Maternal and Child Enquiries (CMACE), and then in 2013 Mothers and Babies: Reducing the Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK), but these bodies have yet to produce an updated report – expected in 2014 – perhaps an indicator that these reviews are extremely resource heavy and slow to produce results, as well as dealing with extremely sensitive material that has to be well managed.[205]

2.5.4 Child Fatality Reviews in HIC

Child fatality review teams were developed in the US in the 1980's primarily to identify victims of child abuse, and are now mandated in many states, as well as in Canada for unnatural deaths, although largely without common reporting and analysis tools, and with a common focus on identifying child abuse and neglect rather than illness.[206-208] The "Arizona Child Fatality Review"[200]in 2002 was a thorough and well described review - they developed a data collection tool which has been the basis for several subsequent studies (including CEMACH). Deaths were notified to a central registry (by legislation) and all relevant records around each case collected and reviewed by local teams comprising representatives of legal, police, medical, welfare and parents to assess for preventability of death and to document circumstances around each death as per the standardized data collection tool. The findings of the study (4806 deaths between 1995 and 1999) were 29% of deaths were preventable. Deaths were classified by age group and by type of death – divided into MVA, drowning, suicide, child abuse, homicide, unexpected infant deaths, other (non-MVC) unintentional injuries, and medical conditions (medical causes comprised 62% of all deaths – largely in infants (77% < one year old of which the biggest groups were prematurity and congenital abnormalities) but just 8% of the medical deaths were considered preventable which gives a good indication of the status of HIC.[200]

Australia mandates reporting of and collection of data on childhood deaths, and some area such as the capital, Canberra, produce detailed reports[209]. The latest 2014 report for the period 2009-2014 reports on 147 death in the area. Most were neonates (46.8%) or infants (60.6%). Main cause of death were extreme prematurity in 28.4%, “medical” causes in 55.0%, and trauma 6.4%, although there are no further details other than demographics and no assessment of the care or even details of the medical causes.

Drife[196] notes a decline in formal mortality reviews and enquiry in the US, likely due to low numbers of deaths, and possibly fear of litigation, although one of the clear findings of maternal mortality confidential enquiries around the world has been the inequalities - with minority groups of women (poor and black in the US) having worse access to healthcare and worse outcome – so there is no room for complacency even in highly developed systems.

2.5.5 Confidential Enquiry in LMIC

In the UK, and in the US it has taken more than 50 years to develop sophisticated confidential enquiries into maternal and child deaths – and this is with legislated and close to 100% reporting and surveillance of every death and a laborious system to collect and analyse the data. But the importance of understanding the underlying factors leading to maternal deaths is seen as such a vital step to improvement that the WHO has come out strongly endorsing such reviews.[210]

The burden of maternal and child deaths rests heavily in LMIC – maternal mortality rates in parts of Europe are (possibly) 2 per 100 000 live births, as compared to Sub-Saharan Africa with a 2010 mean of 500 (but worst case populations have rates in the thousands); and U5MR from 7 in HIC to 109 in Sub-Saharan Africa - so this is where we need to apply what has been learnt for the maximal benefit.[75] In fact maternal mortality reviews have become sporadic in many HIC – the numbers are so few that it is scrutiny of individual cases for questionable (and consequently less confidential) outcome, leading some enquiries to include “near miss” and morbidity enquiries.[196]

In most LMIC there is incomplete (or no) vital registration of deaths so even calculating mortality rates is problematic. Abu Affan[211] commenting on the suitability of confidential enquiries into maternal mortality in LMIC in general, but specifically in Sudan, questions whether LMIC can or should be striving towards such a comprehensive tool. They suggest to start with several different measures (such as census with maternal mortality questions, “sisterhood” enquiry, and hospital records) to collect numbers and data, and from there to develop institutional maternal mortality enquiries starting at major hospitals. There are many successful publications detailing the successes, modifications and limitations in implementing confidential enquiry for maternal mortality in LMIC. Examples include Egypt[212], Ghana[213], Indonesia[213,214], Malaysia[215], Malawi[216], Senegal[217,218] and SA as detailed below.

Probably the key messages from these LMIC studies are firstly that it is feasible, and there would seem to be real benefits to healthcare workers and to maternal morbidity and mortality through implementing such surveillance and enquiry. However the process is not easy and there are many obstacles to overcome in every setting. In 2008 only two countries in Africa could claim complete vital registration of deaths: Mauritius and Seychelles. Even SA still has gaps, maternal deaths coverage is good but limited to facility deaths (around 84% of all births occur in facilities) and registration of child deaths in some rural areas may be as low as 30%.[87]

2.5.6 SA Confidential Enquiry – maternal, child

At present in SA, audits of health facility deaths include the well-established and government driven National Committee on Confidential Enquiries into Maternal Deaths (NCCEMD)[86] since 1998, a Perinatal Problem Identification Program (PPIP)[219] as of the mid 1990s which looks at stillbirths and neonatal (<28 day) deaths, and ChIP[88] since 2003 looking at childhood deaths from birth to 18 years. The latter two audits are facility based, and although growing represent only a minority of voluntarily enrolled facilities (PPIP claims to ascertain around 73% of deaths (2011)[219] and CIPP represents just 42% of facilities (2011)[88]. Clinicians in enrolled facilities identify deaths, collect data internally, discuss at internal mortality meetings and this data is then collated nationally and reported annually (but with a time lag of 2-3 years to publication). All three audits claim at least local success in reducing mortality – although impossible to measure in the context of the HIV epidemic and together publish a report "Every Death Counts" with summary information from the three audits.[87]

Saving Mothers SA Maternal Confidential Enquiry

SA has been formally conducting a national confidential enquiries into maternal deaths since 1997.[86] The methodology used is similar to strategies used elsewhere – maternal deaths are notifiable and following a death a health facility will inform provincial coordinators who allocate an assessor team of a doctor and midwife who assess and establish the details around a death, including cause(s) of death, avoidable factors and missed opportunities; and write a report which is collated nationally and published every three years. The SA assessment team have taken the stance of using the terminology "substandard care" rather than the more widely used "avoidable factors" to describe failures and underlying factors uncovered by the enquiry. They define substandard as "the care that the patient received, or care that was made available to her, fell below the standard which the authors considered should have been offered to her".[86] Also of interest is the concept discussed in the latest report that the problems and issues encountered in mothers who died, are similar to those in "near miss" cases where a mother survived, despite severe organ dysfunction – and this was shown in a study by Mantel[174] – strengthening the argument for death reviews as a convenient sample that reflects problems beyond the deaths. The format of the reporting tool divides care issues into patient related (woman, family, environment (community)); administrative (transport, barriers to access health facility, accessibility, facilities, personnel, staff, communication); and standard of health care (emergency/ admission; resuscitation; anaesthesia).
Ascertainment would seem to be very high, although deaths are only included inside health facilities. The latest report shows that SA MMR is actually increasing – 176 / 100 000 live births (2008-2010) up from 152 (2005-2007). This is mainly blamed on HIV (4/5 maternal deaths were HIV positive). Western Cape MMR is at 85 (2008-2010) but nevertheless up on 73 (2005-7).[86] The main recommendations were targeted at the predominant causes of death: non pregnancy related infections, obstetric haemorrhage and complications of hypertension in pregnancy; through improving knowledge and skills of health care workers. Subsequent estimates are optimistic that these rates are improving following aggressive management of HIV related disease, although it MDG5 which targets a 75% reduction in MMR seems very unlikely.[220]

An insightful commentary from James Drife[221], an obstetrician who has been a key figure in establishing maternal confidential enquiries in the UK, SA and elsewhere is included verbatim below: his response to the high and increasing SA MMR outcomes as reported by the latest Saving Mothers SA report which is resonant to any research, but particularly to confidential enquiries like this thesis.

"In ancient times the reaction to bad news was to kill the messenger, and this instinct still survives. Today when a medical survey brings us unpalatable facts our first reaction is to question its accuracy. Then, if the facts cannot be disproved, we are often tempted to change the way we report them. Some countries, including the UK and many states in the USA, have either discontinued their confidential enquiries or tinkered with them in the hope that by changing the audit system they will speed up improvements in the health system. These efforts are well intended, but they are aimed at the wrong target."[221] *Drife 2012*

SA Paediatric Confidential Enquiry – ChIP

As described earlier, the present SA ChiP program was developed in 2001, piloted in a region and then across several sites in 2004.[222,223] It set out to provide a tool for clinicians to monitor and audit child deaths, using outcome audit (identification of deaths) followed by process audit (in depth scrutiny and assessment of the processes around the death). The enquiry is performed by internal clinicians (who may have managed the child themselves) based on patient records alone. The assessment relies on diagnostic criteria (based on local and national guidelines), clinical judgement and consensus developed at audit/ mortality meetings. The developers at even the pilot stage are clear that a precondition to conducting this type of audit is that clinical personnel agree on standards of care for their practice – and in this case the standards used are local and national standards including: IMCI[224], SA "Package of Care"[225], and SA Standards treatment guidelines and Essential Drug Lists[226] which allows comparison of care received.[223] The ChIP review (available online at http://www.childpip.org.za) uses a standard data collection sheet[227] and looks at the following assessments:

1. Demographics of child from records and Road to Health Chart
2. Cause of Death[228] – by ICD-10 code – single main cause of death, 2 other causes, and multiple contributory causes.
3. HIV classification
4. Modifiable Factors[229] – these are to identify substandard care or missed opportunities for intervention which contributed to the death/ substandard care and could be modified by locally achievable means. They are divided into "who" is responsible":
    - Family/ Caregiver
    - Administrators
    - Clinical Personnel

   And categorized by each site "where" they occur:
    - Ward
    - Emergency and Admissions
    - Referring Facility and Transit
    - Clinic and Outpatient Care
    - Home

   For each who and where, a list has been compiled and the assessor identified each applicable coded modifiable factor, and grades the modifiable factor as "probable" or "possible".
5. A free text summary portion where case, background and problem list are summarized.

The developers following the implementation studies made the comment that ChIP is feasible, but needs commitment and support from clinicians and management for useful data collection and output.[230]

2.5.7 Longitudinal confidential enquiry studies

There are only a small number of longitudinal confidential enquiry like studies in the literature, particularly for paediatric healthcare, so the landmark adult studies and then the few paediatric studies will each be described separately with as much of their methodology and pertinent outcomes as possible.

2.5.7.1 *Adult confidential enquiry*

2.5.7.1.1 McQuillan[30]

McQuillan[30] conducted a 1998 confidential enquiry into the care of 100 adult patients from hospital admission to ICU admission within a tertiary hospital in the UK which is widely referred to around problems in the ward care of critically ill patients and one of the first papers to suggest the need for "early warning score" type identification of critical patients, although possibly flawed in the methodology. They interviewed the admitting team and ICU team (using a structured interview questionnaire). Data from the interviews was then independently assessed by two reviewers from another region (an anaesthetist and a nephrologist) who assessed and judged the quality of care, and avoidability of ICU, and graded various aspects of management of each case. The agreement between the two reviewers was moderate (kappa scores around 0.5), making clear associations to the outcomes difficult. Admission to ICU was at least possibly avoidable in around 46% of patients had they received better management prior to ICU, and at least 39% were admitted late to ICU (*i.e.* earlier admission would have reduced severity). Although there seemed to be clear differences in the outcome of the 54% of patients judged to have had suboptimal care, no clear statistical link was made between quality of care prior to ICU admission and outcome (measured by mortality, ICU physiological scoring, length of stay in ICU, outcome).
Primary causes of suboptimal care were classified (subsequently used by other researchers) as:

i. failure of organization
ii. lack of knowledge
iii. failure to appreciate clinical urgency
iv. lack of experience
v. lack of supervision
vi. failure to seek advice

The authors suggest that their results showed there is extensive suboptimal care, likely in non ICU admissions as well, fundamentally related to failure to recognize and appreciate dysfunction in airway, breathing or circulation. They suggest a medical emergency team to respond to ward patients with early dysfunctions would be more effective than a cardiac arrest team (who is usually too late to reverse physiology). A pertinent quote from there study resonates with the rationale for this study:

"*The greatest impact on the outcome from intensive care units may arise from improvements in input to intensive care particularly in the quality of acute care*."[30] *McQuillan 1998*

Comment[231] and criticism[232] to McQuillan's study was useful and brought in several concepts – ICU being a limited resource, but also the resources of high level care for recognition of deterioration in ward patients' needs to be balanced. Suggested solutions included better senior support/ cover, high care or high dependency units to manage at risk patients, and training of clinicians (doctors and nurses) to recognize at risk patients. Several authors[232] supported the findings of McQuillan and thought they were likely representative of care across the UK. But criticism for the methodology included: the study relied on subjective opinions of two assessors, assessors were aware of the outcome and potentially biased by this, and the definition of suboptimal care was an implicit one, not objectively defined. Suggestions were tighter definitions of “suboptimal care” – objective or explicit definitions, standards or criteria; increase inter-rater reliability by using more assessors and by training of assessors and feedback of results prior to start of data collection; and blinding the assessors to outcome. McQuillan’s research did however seem to spark several studies in the late 1990’s looking at care of the critical and deteriorating ward patient and how to optimize them, including the concept of the “medical emergency team”.

Massey[233] performed a literature review looking at factors influencing ward care in the acutely ill adult patient, from a nursing perspective, and using McQuillan’s classification of the causes of suboptimal care. They found many studies to support McQuillan’s classification system, and clear evidence of suboptimal care in many ward settings, but a lack of specific and contemporary research exploring these factors. She concluded that critical care needs to spread beyond the ICU and be part of a continuum of hospital care to prevent, identify early and expedite care to critically ill and deteriorating patients.

2.5.7.2 ***Paediatric Confidential Enquiry***

Two of the following studies (and a good deal of the third) look at meningococcal infection in children – and important entity in HIC - in many places (such as the UK) it remains the leading infectious cause of death in children.[234] Meningococcal disease is also a tempting disease for studying health care as there is clear evidence that time dependant and simple interventions (early recognition, antibiotics, prompt treatment of shock and ICU support) are lifesaving in this otherwise devastating and aggressive disease in children.[234]

2.5.7.2.1 Nadel[235]

Nadel[235] conducted an important study in 1998, using confidential enquiry methodology to look at meningococcal disease in children, although there is little description on the exact methodology used. They looked at a group of 54 children admitted to a single tertiary PICU in London with meningococcal disease over a two year period. Data collected included medical records from referring general practitioner, referring hospital and tertiary hospital where applicable, in addition to interview with parents and carers to establish onset/ timing. They recognized three stages of health care delivery (or failure): recognition and actions by parents (30% delayed), GP (65% inadequate and/or delayed care) and EC (29% inappropriate care), and after hospital admission (54% suboptimal management – failure to recognize shock, or inappropriate lumbar puncture. Overall only 29% of children received optimal initial treatment pointing to training in recognition and management of seriously ill children as a key issue to address.

2.5.7.2.2 Ninis[236]

Another important confidential enquiry type enquiry on critically ill children was conducted by Ninis[236] in 2003 in the UK – likely a follow on from Nadel[235] with many of the same group involved. Using a clever study design to overcome many of the previous criticisms about outcome bias, lack of case controls and lack of objective measures against which to compare, they looked at all childhood meningococcal deaths in the UK over a 15 month period, and compared the healthcare received by these children who died with those from age and region matched controls who survived their episode of meningococcemia. They collected data on 498 patients (143 deaths, 355 survivors) from all relevant medical records. These records were then assimilated and presented to a panel (4 from paediatrics, EM and PICU specialities), revealing the course and management received from presentation an hour at a time (thus only revealing the outcome after final assessment). For each hourly assessment they compared the care received to clear cut accepted and published criteria- looking specifically at failure of care (delay > one hour from panel assessed need to treat until actual – be it because of failure to recognize a complication or failure to recognize the severity) and failure of supervision (>24 hours delay to being seen by consultant). Cases were controlled as far as possible for disease severity using a prognostication score at first presentation. The outcomes showed significantly more management failures in those children who died – thus supporting the hypothesis that suboptimal care contributed to poor outcome in this disease and population. Significant factors associated with death included failure to recognize severity and complications, lack of supervision and paediatric involvement, and inadequate fluids and inotrope support. Authors came out with some very specific reasons for suboptimal care which are important for paediatric critical care:

- Vital signs missed or inadequately documented
- Normal ranges of vital signs for different age groups not taken into account
- Lack of recognition and appreciation of compensated shock in children
- Lack of insight and appreciation for speed of disease progression in children (especially in junior staff and those inexperienced in paediatric care)

They point to practitioners who deal primarily with adults especially as not being cognisant with age appropriate normal vital signs, and especially being too reliant on hypotension which is a late sign in children.

2.5.7.2.3 Launay[237]

Published in 2010, Launay[237], performed a confidential enquiry into childhood deaths from severe bacterial infection within an entire population in a region of France over a five year period. They included children (3 months -14 years) who died either in the regional tertiary hospital or at home from suspected bacterial sepsis and double checked these cases against the national death database to ensure comprehensive inclusion of all cases in the geographical area. For each child clinicians assimilated data from medical records in a pre-established template focusing on history, sequence events, presenting symptoms and signs and treatment. Two independent experts (a paediatrician and a paediatric intensivist/ EM specialist) then reviewed each case and judged the care to be optimal/ possibly sub-optimal/ sub-optimal relative to specific national and international criteria (for delay, timing of antibiotics and haemodynamic support). Over the five year period, just 21 children were enrolled, predominantly with meningococcemia, of which the authors reported 16/21 (76%) to have been less than optimally managed. Commonest errors were delay in fluid/ antibiotic administration; dose errors (especially inadequate fluid resuscitation); underestimation of severity; and parental delay in seeking help. Reviewers were blinded to the final outcome but had insight to the clinical course. Findings were largely consistent with those of similar studies (Nadel and Ninis)[235,236]. Although this study was not able to link suboptimal care with poor outcome, other studies looking at effects of interventions on sepsis have suggested that improving quality of care (especially delays, timing of antibiotics, early and adequate fluid resuscitation, and compliance with bundles of care) do improve outcome in septic shock.[24,236,238,239]

2.5.8 Other Confidential Enquiry Issues – ethics *etc.*

In a country where the death of a mother or child is a rare event (such as in the UK where the likelihood of a pregnant mother dying is a 1 in 5000), such deaths are met with anger, media stories, desire to apportion blame, and concerns over individual and institutional reputation.[196] Whereas in LMIC (as in Europe in the last century), death is a regular occurrence – most people know a family affected by a child or mother's death.

In HIC, with a child's death being such a rare and catastrophic event, there is a delicate balance between maintaining patient confidentiality (especially in the light that there is no consent from the patient/ family in most confidential enquiry cases); and the benefit of detailed (perhaps identifying) data to an enquiry to improve healthcare for others.[240] The balance is a critical one, but even a "Citizen's Council" of UK community members[241] who were asked their opinions were happy to concede that the benefits of confidential enquiries outweighed the potential harms of performing without specific consent, so when performed rigorously, these studies are unlikely to impinge on the ethics of the deceased or their family.

Equally, confidential enquiries, in order to maintain credibility and to keep information sources open, need to protect the health practitioners and facilities. Clinicians in the UK, where confidential enquiries are entrenched from early training, are positive – they see the enquiries as an integral and essential part of their practice and quality improvement.[196] Rankin[242] questioned the impact of confidential enquiries on the actual participants (the panellists in various UK confidential enquiries) and they were also largely positive about the experience – claiming it was a learning experience from a spectrum of multidisciplinary colleagues with impact on personal practice – such that they advocated the potentials of the methodology for teaching. Participants did however voice concerns: there is not enough focus on good practice - too much criticism can be demotivating; and feedback to individual units and facilities is often inadequate (difficult to overcome given the blame free and confidential approach).

3 METHODOLOGY

3.1 Pilot Study

To examine the potential and feasibility of conducting a research program looking at the entire pathway that a critically ill or injured child undergoes in the healthcare system, from first presentation until PICU admission or death, a pilot study was conducted in 2007 from the RCWMCH PICU (unpublished data Ward & Argent 2008). Over a four week period (October/ November 2007), there were 44 emergency PICU admissions and four EC deaths at RCWMCH. For each child, the involved health facilities and EMS transfers were identified, and all medical records were collected. Almost two thirds (61%) of children had been through at least three "steps" in their pathway prior to arrival at RCWMCH (an EMS transfer constituting a step in this study). The study revealed the difficulty in establishing the pathway; the poor documentation by clinicians and health facilities; and the difficulty in obtaining records outside of RCWMCH: complete records were only available in less than a third of cases (7-36%), although the essential information could be established in half of cases (47-48%).

An expert review panel (Wallis and Argent) was established who reviewed the data. The pilot study was not powered to quantify the "modifiable critical care events" they identified, but the most frequent were:

- inappropriate delay in seeking and provision of medical care
- inadequate and delayed triage in primary and emergency care
- failure to initiate appropriate respiratory and circulatory support
- failure to appropriately involve senior staff
- delay in onward referral in primary care
- delay to ambulance transport
- delays and inadequate monitoring during transport
- delay in admission to PICU

There were gaps in the records, particularly around timelines which the team was not able to identify and often could only be established by discussion with the hospital staff involved in the management (which required the follow up to be done rapidly while the incident was still fresh in the minds of all involved). The workload of gathering the data was such that it was decided that collection in alternate weeks only would make further studies feasible, and also that interviewing the caregivers of children, often available waiting with their children once they are admitted to PICU, would add valuable information.

The central hypothesis was that the study would identify issues impeding effective paediatric critical care, and give evidence for cost effective interventions. From these findings, a study was designed to select a representative sample of critically ill and injured children admitted to the RCWMCH PICU; and a sample of paediatric deaths occurring in the EC of RCWMCH and at a sample of the referring facilities. For each child, information on the entire acute health care episode - from first presentation to the health care system, through referral at perhaps multiple sites and EMS transfer(s) to PICU admission or death – would be gathered from medical records and a semi-structured interview conducted with the parent/ caregiver of the child. An expert clinical review would then be undertaken of these data in order to identify preventable failures in care contributing to unnecessary morbidity and mortality.

3.2 POPULATION AND STUDY SAMPLE

The study selected a representative sample of critically ill and injured children admitted to the RCWMCH PICU, and a sample of paediatric deaths occurring in the EC of RCWMCH and at a sample of the referring facilities (as described below).

Power Calculations

Based on pilot study data, PICU admission data and expected deaths, it was calculated that the sample would give over 400 eligible participants. Power calculations were based on ascertainment of 300 PICU admissions and 80 deaths providing reasonable precision in estimating the proportion of children suffering from critical care failures (*i.e.* major modifiable factors in their care). For example, a proportion of 40% will be estimated with 95% CI of ± 5. Including deaths at facilities outside of RCWMCH would further increase precision, but we were unable to pilot ascertainment of these cases.

Inclusion and Exclusion

Following the pilot study looking at the feasibility of such research, the study was restricted to cases with an acute healthcare presentation, and to sample some (alternate week) rather than all PICU admissions due to the logistics of a small research team conducting interviews for each enrolled child, as well as physically collecting and copying paper-based medical records from multiple distant facilities for each case. Table 3-1 shows the criteria used to screen for eligible patients. The sampling of facilities to include for the deaths outside of RCWMCH was simplified to include all public sector health facilities with 24 hour ECs in the direct referral area of RCWMCH. This included three hospital (two district and one regional); and five CHCs. This represented a meaningful, yet feasible number of facilities (there being many more in the metropol), and patients from these facilities would be from the same setting as the rest of the cohort.

Table 3-1 Inclusion and Exclusion Criteria

Inclusion Criteria:

- Emergency PICU admissions over a year (1 November 2011 to 31 October 2012) sampling alternate week PICU admissions (Sunday 8h00 to following Sunday 7h59)
- Paediatric deaths in the RCWMCH EC
- Paediatric Deaths from a sample of the immediate geographic referring hospitals and CHCs – one regional hospital, two district hospitals and five 24 hour CHCs

Exclusion Criteria:

- Consent not obtained (refusal, unable to contact or language barrier)
- Age greater than 13 years (upper prescribed age limit for RCWMCH admission)
- Elective PICU admissions and their complications
- Patients admitted in hospital for more than 5 days prior to PICU admission
- Death following a palliative care decision
- Neonates admitted directly from obstetric services
- Deaths occurring prior to arrival at a health care facility (*i.e.* “death on arrival” with no signs of life and no attempt at resuscitation by healthcare facility)

3.3 ASCERTAINMENT

Following the pilot study (conducted in 2007), a successful grant application was made to the Wellcome Trust and a research team was employed to conduct the research in early 2011.
The study protocol (***Appendix VI***) was then developed into a research project. Ethics approval was obtained from the University of Cape Town Human Research Ethics Committee, as well as the Oxford University Tropical Research Ethics Committee)(***Appendix I***); followed by approval and consent to conduct the study from the Western Cape Provincial Health Department (which gave authority to collect data at any facility in the Province where an enrolled child had been seen, as well as the data for children who had died at the specified facilities), from the City of Cape Town (for Clinics which are administered by them), and from RCWMCH where the study was based, and by the nature of the enrolment was involved in most cases (***Appendix II***). Data collection tools and an online database were developed, and a research team recruited and trained. The full time research team consisted of three interviewers (able to speak the three major languages between them) to consent and interview; two research sisters to screen, co-ordinate medical record collection and for data entry; a data clerk to locate and copy medical records at each identified facility; and a clinical fellow with an EM background to review each case. The three expert reviewers, heads of departments from UCT paediatric critical care, EM and PHC, spent considerable time on the review process – around 4 days a month, in addition to bi-weekly consensus meetings.

A study overview group was formed consisting of the UCT Dean of Health Sciences, the Director of Hospital Based Health Services for the Western Cape Department of Health, and the Health Director from the City of Cape Town City Health Department to endorse the study, and to ensure that results were fed back to the system and that there was the potential for both educational and service delivery response.

For the month prior to the start of data collection, the research and interview teams were trained, and a pilot phase with the full enrolment and collection of data for 20 cases was conducted. This enabled real time training of all members of the research team, fine tuning of all elements of the research process and trialling and optimizing of the online database. These 20 “pilot” cases were not included in the data analysis.

Figure 3-1 gives a graphical outline of the process (and the roles of reviewers), and Figure 3-2 provides more details around the review process. It was thought that a key issue in obtaining high quality data in the pilot was promptness (hot-pursuit) to ensure facility and EMS documents were easily obtainable, that key clinicians could be contacted within a reasonable time period for further information, and that caregivers were interviewed as soon as reasonably possible after the episode. Forging relationships with key personnel at each facility were also key to successful record collection due to the sometimes chaotic environments and somewhat erratic filing systems.

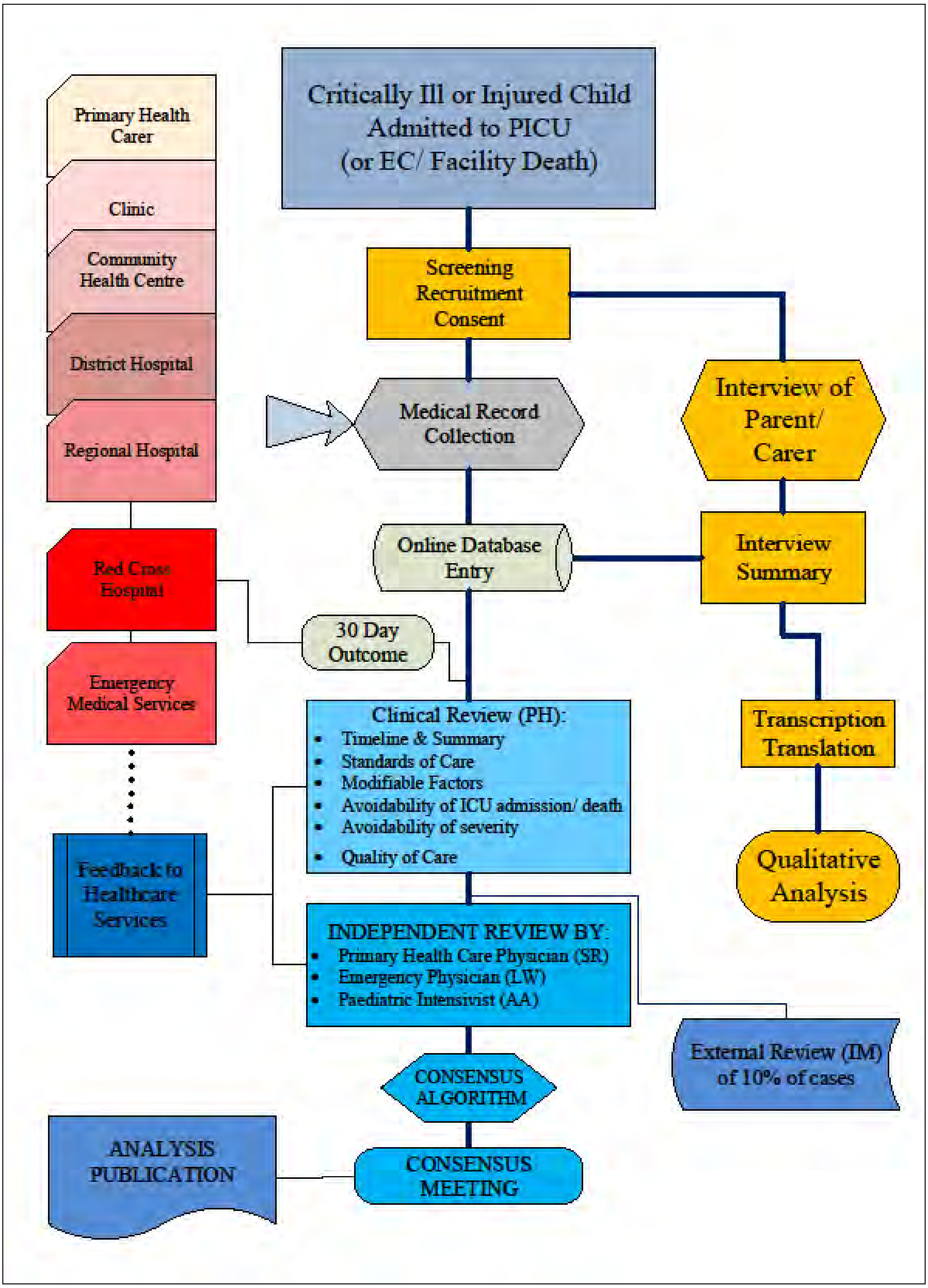


Figure 3-1 Schematic of Pathways to Care Research Project

EC emergency centre; PICU paediatric intensive care unit; PH Peter Hodkinson; SR Steve Reid; LW Lee Wallis; AA Andrew Argent; IM Ian Maconochie

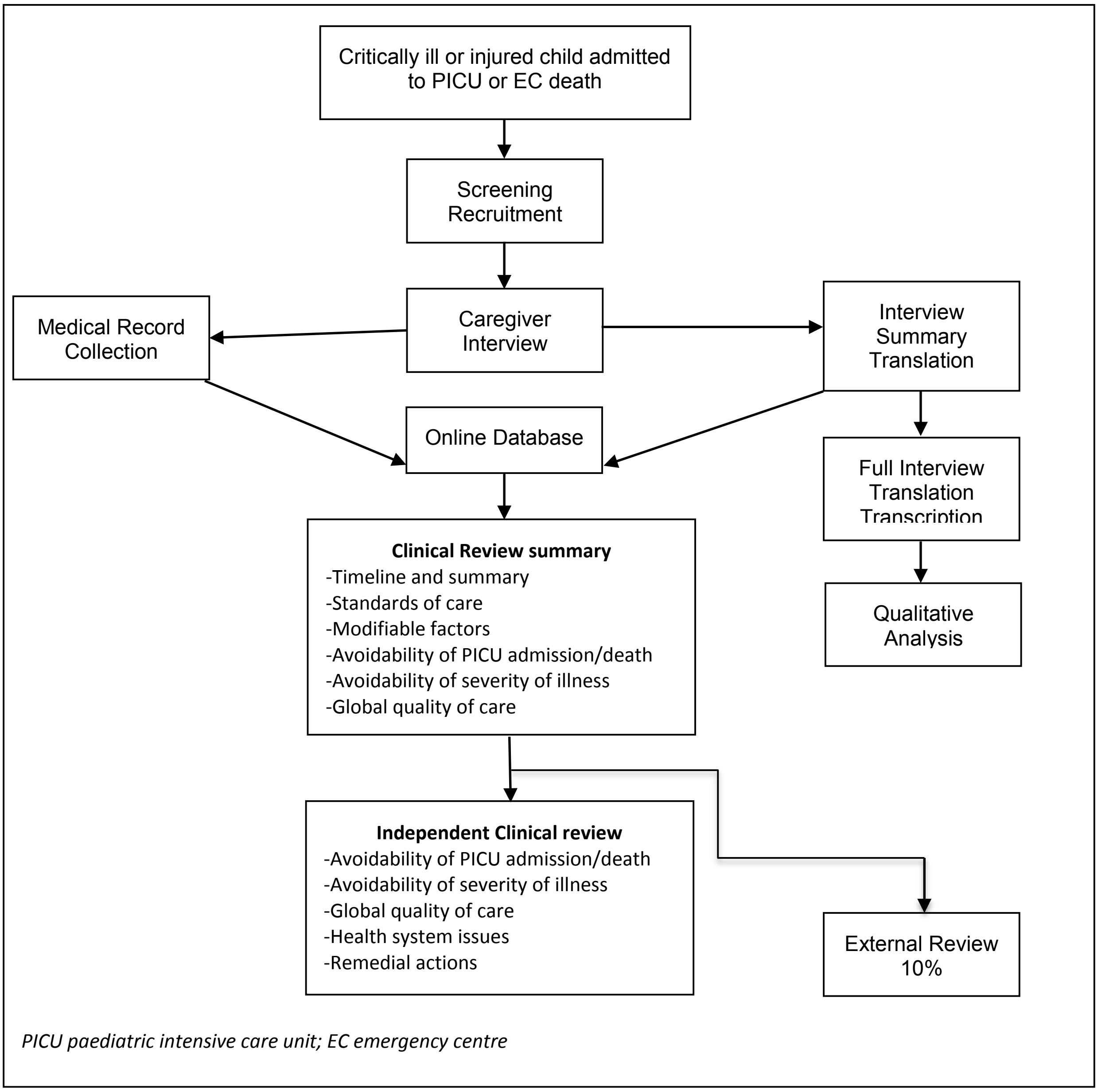


Figure 3-2 Schematic of Review Process

3.3.1 Recruitment and Screening

Patients were identified daily in the PICU and eligible patients were approached by an interviewer soon after PICU admission. Caregivers of children who were not present in the PICU following admission were contacted telephonically and an interview arranged at their convenience.

Of particular difficulty was the identification and follow up of caregivers of children who had died prior to PICU admission, be it in the RCWMH EC or at other facilities, for these parents were not available visiting or staying with their children in the PICU (as other parents usually were) and had left the facility following the death of their child. We identified and traced these deaths through multiple sources – clinical managers at each site informed us of any paediatric deaths, key clerical staff at each facility were contacted regularly to check for EC deaths, and death registers at each facility were manually checked. The available death registers did not distinguish between adult and paediatric cases, and especially between those dying at home, outside, or inside a health facility. So although imperfect we were reasonably certain that we captured the majority of eligible deaths and they were generally contacted telephonically, or in a few cases by home visits when there was no telephone number available. The caregivers of these children were contacted telephonically within 2-3 weeks of the child's death,

3.3.2 Medical Records

All medical records related to the episode of care at each facility along the pathway were collected - included records from EMS, regional and district hospitals, CHCs, clinics, and RCWMCH (including wards, operating theatres and EC, as well as RCWMCH laboratory and radiology results, up to and including the first assessment on admission to PICU). Relevant sections of the (paper) records at each source were obtained, photographed and loaded onto an online secure database. A full time data collector drove around to identify facilities on a daily basis to collect such data, having established credentials and relationships early in the study with frequently visited facilities.

Records were not sought from any private sector hospitals and general practitioners (although in most cases there was a referral letter with the receiving facility documents). This was because the numbers of patients consulting there was envisaged to be small, and they were not reflective of the health system being evaluated. In addition because of the complexity of organizations and facilities in the private sector, and the large number of general practitioners with no central organization or information available on their practises, it was not feasible to contact them all in advance and to collect data from them.

3.3.2.1 *Interview*

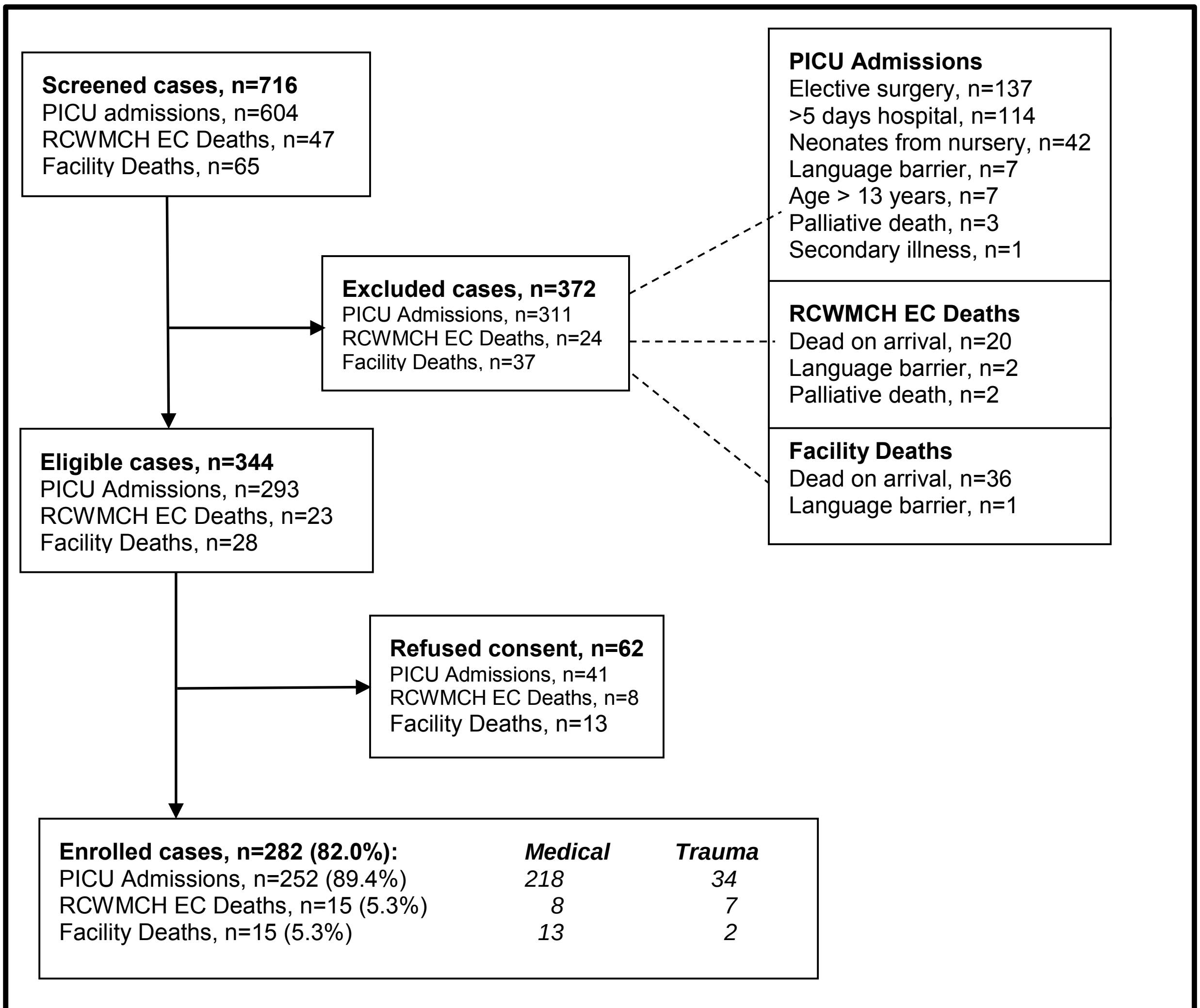
Following the consent process, a semi-structured interview was conducted with the parent/ primary caregiver of each enrolled child. This was conducted in a private setting (usually the counselling room adjacent to PICU), by a trained and experienced interviewer (in the caregiver's home language) as soon as possible after PICU admission/ death. The focus was on the caregiver's narrative of the episode, with probing questions around household demographics and socio-economics, access to health care, timeline and delays, undocumented issues and insights, and perceptions and satisfaction with health care facilities, and providers. Each interview was summarized and this and the demographics, timeline and general information was entered into a database by the interviewer. The interviews were recorded, transcribed and translated for subsequent qualitative analysis. ***Appendix VIII*** gives the details of the specific interview data collected and entered into the database.

3.3.2.2 *Outcome Data*

For those admitted to PICU, data were collected from PICU and hospital databases on the PICU outcome including the Paediatric Index of Mortality (PIM2)[2], length of stay in PICU, the final diagnosis, length of stay in RCWMCH and the 30 day disposition of the child (*i.e.* still in PICU, still in RCWMCH, discharge home, or death).

3.3.2.3 *Screening and Enrolment Data Results*

In the 12 month period, 1st November 2011 to 31st October 2012, 716 cases were screened, 344 eligible cases were identified (311 PICU admissions and 61 deaths) and 282 cases were enrolled - giving a recruitment rate of 82.0% (Figure 3-3). These patients were seen at 612 facilities prior to their ICU admission/ death, and underwent 298 EMS transfers. Admissions to the PICU made up 252 cases (89.4 %), deaths in RCWMCH EC 15 (5.3%) and deaths at other sampled facilities 15 (5.3%).



RCWMCH – Red Cross War Memorial Children's Hospital; PICU paediatric intensive care unit; EC emergency centre

Figure 3-3 Screening and Enrolment Process

Enrolment varied over the 12 month study period as shown in Figure 3-4, with a range of 15-35 children and mean of 24 per month (medical mean 20, range 14-32; and trauma mean 4; range 0-8). The reason for low enrolment in July was not understood, but otherwise the trend seems to be more enrolments in the winter season which is as expected.

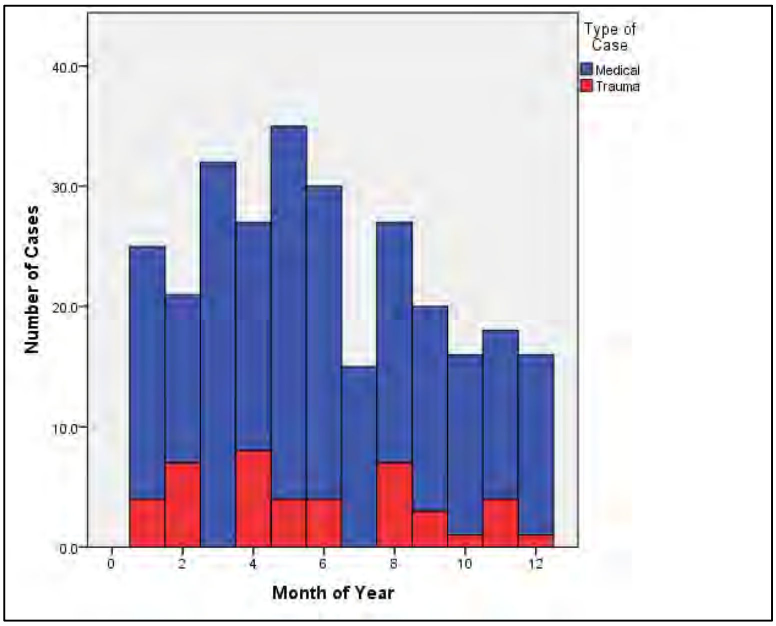


Figure 3-4 Patient enrolment throughout the collection period

3.4 Data management: Online Database

An online database was developed to allow entry, access and secure storage of: digitized medical records (nursing and medical notes, laboratory results, radiology and PICU discharge summaries), pathway times, vitals and medical management, interview summary and timelines. By allowing each team member individual login and specified limited access, it also facilitated a blinded independent review, comment and grading of cases by an expert panel. Algorithms in the database calculated consensus for all reviewers on each case, as well as communication between team members, monitoring of all aspects, and on-going analysis. ***Appendix IX*** gives details of specific quantitative data entered into the database. ***Appendix X*** shows some pertinent screenshots which demonstrate the online database functionality.

3.5 Review Process

The clinical fellow (PH) collated, summarized and reviewed each case, developing a clear timeline of the pathway (with the insight of both the record and interview data). Rarely, gaps or conflicting issues were referred back to the collection team, or in some cases to the clinicians involved for clarification.

3.5.1 Standards

Care at each facility and EMS transfer was assessed for compliance with locally developed consensus standards of care for paediatric emergency care by the clinical fellow and reviewed by the three expert reviewers. The standards were stratified by the review team into 3 levels according to their impact on patient care -: critical, important and fundamental. The development and assessment of these standards is described in detail in Chapter 9 (a summarized version can be found in Table 9-2).

3.5.2 Modifiable Factors

A list of potential modifiable factors was compiled as shown in Table 3-2. This was based on a review of the modifiable factors identified in the Confidential Enquiry into Maternal and Child Health in the UK[53,197,199,243], the modifiable factors used in ChIP[87,223,229], outcomes of a Delphi study conducted in Nairobi by Ntoburi[244];

as well as from pilot study data. The list was refined as the project developed, and finalized during the pre-data collection pilot phase. Definitions were developed for the possible impact of these factors: no impact; minor/moderate impact; near miss and major impact as shown in Table 3-3. Each facility and EMS transfer was assessed and graded for any of these applicable modifiable factors.

Table 3-2 List of Potential Modifiable Factors

FACILITY	**COMMUNICATION**
Accessibility of Emergency Care area/ personnel	Explanation to caregiver
TRIAGE	Communication death issues
Inadequate assessment at triage	Other
Triage mechanism misses critical patient	**EMS**
Other	Communication with call centre at initiation of transfer
INITIAL ASSESSMENT	Communication from control to dispatched crew
Missing key findings (history/ clinical)	Prioritization of call out
Inadequate assessment/ interpretation of severity	Dispatch time delay
Investigations inadequate	Transfer time excessive
Investigations excessive	Response time delay
Missed/ incorrect diagnosis	Inappropriate vehicle/ crew/ equipment
Other	Inadequate stabilization for transfer
MANAGEMENT	Inadequate assessment before transfer
Delay in critical management decisions	Inadequate monitoring en route
Resuscitation not done/ inadequate for shock	EMS clinical management decision
Airway management	EMS disposal decision
Ventilatory management	Other
Circulatory management	**OPERATING THEATRE (those not covered above)**
Haemo-glucose test assessment and management	Anaesthetic Pre-op Assessment Inadequate
Antibiotic therapy	Anaesthetic Senior not called pre-op
Analgesia	Surgical Pre-op Assessment Inadequate
Temperature management	Surgical Senior not called pre-op
Electrolyte abnormality management	Delay pre-op
Trauma Immobilization	Anaesthetic technique
Delay in disposal decisions	Fluid Management
Other	Surgical technique
CONSULTATION	Delay on table
Inadequate supervision of junior staff	Delay in calling senior for assistance
No consultation to on site seniors	Recovery Process issues
No consultation to offsite specialists	Delay in transfer out
Senior review of patients (e.g. ward round) inadequate	Other
Delayed consultation	**DOCUMENTATION**
Other	Missing date/ times
REFERRAL	Missing / poorly documented information
Inappropriate referral destination	Other document issues
Communications with receiving facility	**RADIOLOGY**
Call/ information given to EMS about transfer	Delay awaiting radiology
Inappropriate referral mechanism (e.g. taxi/ private transport)	Delay in performing radiology
Inadequate stabilization for transfer	Delay reporting radiology
Ongoing monitoring/ management while awaiting transfer	Radiology findings missed/ misinterpreted
Referral Delay	Other
Other	**ADVICE TO PARENTS**
	No documentation of advice given
	No documentation but parents recall advice

PICU paediatric intensive care unit; EMS emergency medical services

Table 3-3 Definitions of Impact of Modifiable Factors

No Defined Impact – factor which has no individual or cumulative negative impact on the outcome of this or future cases **Not known** – cannot be established or estimated given facts known about scenario **Moderate Impact** – factor which on its own had minimal negative impact on the outcome but may have caused some morbidity and/ or extended the hospital/ PICU stay **Near Miss** – unplanned event that did not have major impact– but had the potential to do so - only a fortunate break in the chain of events prevented an injury, fatality or damage **Major Impact** – factor which had clear negative impact on the outcome of the patient (worsened mortality or morbidity); directly and overwhelmingly important factor in the severity of illness/ death·

3.5.3 Grading of Care and Avoidability

The clinical fellow and three physicians, one each from paediatric intensive care (AA), emergency medicine (LW), and primary care (SR) then each independently reviewed each case using all available information. The care delivered for each child at each facility and during EMS transfer was assessed.

Outcomes for each child:

1. Overall global quality of care for the entire pathway (good/ fair/ poor - relative to the contextual expectation for the case).
2. Avoidability of death (avoidable/ potentially avoidable/ not avoidable)
3. Avoidability of PICU admission (avoidable/ potentially avoidable/ not avoidable)
4. Avoidability of severity of illness on PICU admission (avoidable/ potentially avoidable/ not avoidable)
5. Number and type of modifiable factors per case
6. Presence of healthcare system issues -system issues beyond the acute episode which contributed to the health status of the child at presentation (for example missed prior opportunities at intervention, or inadequate follow up and referral).

Outcomes for each facility/ facility level

7. Number and type of modifiable factors
8. Quality of care for each child relative to expectations for individual facility/ transfer

Algorithms in the database (Table 3-4 and Table 3-5) then calculated consensus between the reviewers (for global quality of care (QOC), avoidability of death/ PICU and severity) – when this was conflicting, the case was identified and discussed at a bi-weekly consensus meeting attended by all reviewers and the clinical fellow, until agreement was established.

Table 3-4 Algorithm used to calculate agreement between internal reviewers for Global Assessment of Care

reviewer ratings#	**Poor**	**Fair**	**Good**
Poor	Agreement	≥2/4 rate as fair → = Fair, <2 = poor	any good & poor = for discussion
Fair		Agreement	≥2/4 rate good → = good, <2 = fair
Good			Agreement

reviewer ratings were compared on the x and y axes of the algorithm, to assess for consensus, or disagreement that needed to be discussed at a consensus meeting.

Table 3-5 Algorithm used to calculate agreement between internal reviewers for Avoidability of Death/ PICU Admission/ Severity

reviewer ratings	**Avoidable**	**Potentially Avoidable**	**Not Avoidable**
Avoidable	Agreement	≥2/4 rate as avoidable → = avoidable, <2 = potentially avoidable	any combination of avoidable and not avoidable = discussion
Potentially Avoidable		Agreement	any combination of potentially avoidable and not avoidable = discussion
Not Avoidable			Agreement

reviewer ratings were compared on the x and y axes of the algorithm, to assess for consensus, or disagreement that needed to be discussed at a consensus meeting.

3.5.4 External Review

An external reviewer (Dr Ian Maconochie, a London based, international expert in paediatric EM and critical care) randomly reviewed 10% of cases based, blinded to the other reviewer gradings. At the start of the review process, all the reviewers including the external reviewer attended a day of introduction and training on the database and review process to clarify what was required of them. The external reviewer reviewed all of the first 10 cases, and each was discussed to ensure clarity and uniformity of the review process. After that one case in every 10 completed cases was randomly assigned to the external reviewer to review, in the same way as the internal reviewers – *i.e.* blinded to the other reviewer's gradings and assessments. All the reviewers were encouraged to make free text comments on how the care could have been improved, and particularly on the system issues which may have been present or avoidable prior to the acute presentation.

3.6 DATA ANALYSIS

The data analysis was observational including:

1) a child-based analysis, developing a graphical method to display the different care pathways and timing of events
2) a child-based analysis, tabulating the proportion of children suffering modifiable critical care incidents.
3) a critical event based analysis, tabulating the frequency of different types of modifiable critical care incidents and their severity.
4) a theme-based categorical analysis, seeking to exemplify key issues from a limited number of case-histories of individual children.

For demographics, diagnosis, pathway variables, and modifiable factors, descriptive data (median and interquartile ranges) was used, or mean and standard deviation (where they were normally distributed)), and presented findings separately for children and facilities. To assess agreement between each of the reviewers' blinded assessments (of outcomes 1-4) and the final consensus assessment, kappa statistics were estimated.[245]

Multivariable linear regression was used to explore independent predictors of the risk of mortality on admission to PICU and the major clinical outcomes for those admitted to PICU (length of stay in RCWMCH, length of stay in PICU). Multivariable logistic regression was used to explore independent predictors of the outcome "dead at 30 days". Gender, age, and expected weight for age (z-score) were entered into the linear regression analyses as fixed variables (regardless of association with the outcomes at univariate level). Due to the low number of deaths (n=47), no fixed variables were entered into the logistic regression analysis. Additional demographic variables, diagnosis, pathway variables, and global assessment of care were entered into the regression analyses if there was a univariate association with the outcomes of $p<0{\cdot}2$. Stepwise regression was used to determine a final model where the additional variables were only retained if they were significant at $p<0{\cdot}05$. Trauma cases were excluded from the regression analyses to reduce the heterogeneity of the sample.

Where appropriate, the quantifiable data were presented using standard statistical methods (parametric or non-parametric). Analysis was performed with the online database, and SPSS (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.).

In parallel a sample of the interviews were transcribed and translated for qualitative analysis to further explore and add depth to key themes identified.

3.7 ETHICAL CONSIDERATIONS AND PATIENT CONSENT

This study presented many ethical issues for the research teams – primarily around the parental consent/ interview and protection of identities of minors. In addition there was contention around identification and recriminations to individual health care workers and facilities, as well as the confidentiality and issues around accessing and copying of medical records.

Conducting interviews with the parents/ caregivers of children who had recently been severely ill, injured or died is perhaps contentious but there is good evidence suggesting that conducted appropriately and sensitively, interviews in such cases are unlikely to be harmful and may actually be beneficial.[246-252]

Following the interview process, caregivers were asked whether they found the interview stressful, and whether they would be prepared to participate in similar research in future. The overwhelming majority said the interview was not at all stressful (76.6% overall (and 46.7% of those whose children died prior to PICU)), while 14.8% said it was a somewhat to a little stressful, and 20 caregivers (7.1%) found it very stressful. The length of the interview was thought to be about right by 91.1%; and 88.7% (including 76.7% of those whose children died prior to PICU) of caregivers were prepared to participate in further interviews if necessary, indicating widespread positive feelings about the process, even following the tragedy of a recent death and discussing the circumstances of the death.

The research team undertook that in cases of grave negligence or clear caregiver request for help or intervention we would inform/ refer the caregiver/ patient onto relevant management structures for their intervention. Over the year long period of the study, there were 12 cases that the team referred to relevant management to investigate. Five of these cases were deaths prior to PICU and related to lack of communication with caregivers following the death of a child, and the others related to specific perceived mismanagement at facilities or EMS.

Ethics approval for the study was obtained from the University of Cape Town and Oxford University. (***Appendix I)***. Approval was also obtained from the Western Cape Department of Health and the City of Cape Town to conduct the research across all facilities in the province (***Appendix II***). Patient, health facility and health care practitioner identities were known only to the research team and were protected and encoded.

3.8 DATA VERIFICATION

At the completion of the data collection, a randomly selected 10% of cases underwent data verification, which revealed an error rate of 2.5% in the data entry, with the errors being largely inconsequential such as duplicate data contradictions (e.g. date of birth between hospital records and that given by the parent), misspelling or rarely time/ date errors. The data cleaning process (assisted by the electronic database) facilitated correction of many of these errors, with reference to original records being made where there was ambiguity.

3.9 Conclusion

This study presents a novel approach to identifying and quantifying flaws in the healthcare system at all levels. It is immensely more difficult to analyse multiple systems rather than individual facilities and it was believed that this case-based approach would prove powerful and informative and offer a model for systems research elsewhere. The study elucidated the detailed management and referral care pathways of critically ill and injured children throughout the health system, and will enable the identification of critical points where intervention is likely to have most impact. This information is essential for further improvement of systems and training processes.

The methodology of the study, including strengths and weaknesses and general discussion is included in the Main Discussion, Chapter 10.

4 DEMOGRAPHICS AND DESCRIPTION OF COHORT

4.1 DEMOGRAPHICS

The baseline characteristics of the enrolled cohort of children are presented in Table 4-1. Over half (58·2%) of the children were male (63% of the trauma cases were male). More than two thirds (67.8%) of medical patients were under one year of age, and 51.2% of trauma patients were more than five years of age. Xhosa was the main language spoken followed by Afrikaans. Only a third of households had an income over R2500 per month. The majority of carers were single (59%) and the mean age of the mothers was 28.6 (SD 6.6) years and father 33.0 (SD 8.5). HIV prevalence (2012) in the antenatal population in the Western Cape province is 16.9% (and 18.6% for the Cape Town Metro)[253]; yet in this cohort 25.3% of the cases (where there was data) were exposed at birth to HIV, but only 9.3% were infected.

4.2 DIAGNOSIS

Of the 282 cases, 43 (15.2%) were trauma, and 239 (84.8%) medical. Trauma cases were predominantly (28 (65.1%)) a result of road traffic accidents, with the remainder burns (8 (18.6%)) and other injuries. Trauma patients in the study had a median age of 63.5 months (IQR 23.5 – 100.6) with 62.8% male. Medical patients on the other hand had a median age of just 4.7 months (IQR 2.2 – 20.2), 57.3% male and the main diagnoses are shown Table 4-1. Many cases presented with multiple pathologies, so this presents the principal acute reason for ICU admission or death.

4.2.1.1 *Medical Cases*

Acute respiratory infections and gastro-enteritis accounted for over a third of cases as shown in Table 4-2. Where available, data on the birth weight of children showed a small number of medical cases (10.9%) were very low birth weight (VLBW), a quarter low birth weight (LBW) and the remainder normal weight. Of note caregivers of older children (viz. trauma cases) were less likely to recall the birth weight of a child so these data are incomplete and may be skewed. Weight for age demonstrated a third of patients (all medical) to be underweight (although this will have been skewed by the many infants with low birth weight – *i.e.* the weights are not corrected for gestational age).

Pre-existing conditions were present in 49 (20.5%) of the medical cases – 38 had an underlying congenital cardiac lesion, four other congenital abnormality (non-cardiac), and seven a chromosomal abnormality.

Table 4-1 Baseline characteristics of the enrolled children

	Medical (n=239)	Trauma (n=43)	Total (n=282)
Gender: Male	137(57·3%)	27(62·8%)	164(58·2%)
Age Median (months) (IQR)	4·8(2·2-20·2)	63·5(23·5-63·5)	7·8(2·5-33·6)
<1 month	30(12·6%)	0(0·0%)	30(10·6%)
1 month to 1 year	132(55·2%)	5(11·6%)	137(48·6%)
1 year to 5 years	55(23·0%)	16(37·2%)	71(25·2%)
>5 years	22(9·2%)	22(51·2%)	44(15·6%)
Language spoken by caregiver Xhosa	148(61·9%)	24(55·8%)	172(61·0%)
Afrikaans	61(25·5%)	15(34·9%)	76(27·0%)
Other	30(12·6%)	4(9·3%)	34(12·1%)
Household income per month	(n=232)	(n=41)	(n=273)
<R1000	93(40·1%)	11(26·8%)	104(38·1%)
R 1000- R2 500	72(31·0%)	12(29·3%)	84(30·8%)
>R2 500	67(28·9%)	18(43·9%)	85(31·1%)
Caregiver's marital status	(n=236)	(n=40)	(n=276)
Single	137(58·1%)	25(62·5%)	162(58·7%)
Married	86(36·4%)	12(30·0%)	98(35·5%)
Other (divorced/ widowed/ long term partner)	13(5·5%)	3(7·5%)	16(5·8%)
Distance from Health Facility			
Nearest facility (km) Median(IQR)	2·0(0·8-4·0)	1·0(0·5-2·0)	2·0(0·5-3·0)
Nearest 24 hour facility (km) Median(IQR)	6·0(3·0-12·0)	7·0(2·0-15·0)	6·0(2·5-13·0)
Mother's age Mean (years) (SD)	28·6 (6·6)	31·3(8·5)	28·9(7·0)
Number of Siblings Median (range)	2(0-6)	2(0-5)	2(0-6)
Expected weight for age (z-score)*	(n=227)	(n=32)	(n=259)
z < -3	67(29·5%)	0(0·0%)	67(25·9%)
-3 < z < -2	30(13·2%)	0(0·0%)	30(11·6%)
z > -2	130(57·3%)	32(100%)	162(62·5%)
Diagnosis	(n=239)	(n=43)	(n=282)
Trauma+	-	43(100·0%)	43(15·3%)
Cardiac++	30(12·6%)	-	30(10·6%)
Gastro-enteritis	13(5·4%)	-	13(4·6%)
Neurological-meningitis/epilepsy**	20(8·4%)	-	20(7·1%)
Respiratory Disease#	102(42·7%)	-	102(36·2%)
Sepsis/ septic shock##	42(17·6%)	-	42(14·9%)
Other***	32(13·4%)	-	32(11·3%)
HIV status [x]	(n=204)	(n=1)	(n=205)
Negative (unexposed)	130(65·0%)	4(80·0%)	134(65·4%)
Negative (exposed)	46(23·05%)	1(20·0%)	47(22·9%)
Exposed (no result)	5(2·5%)	0(0·0%)	5(2·4%)
Infected	19(9·5%)	0(0·0%)	19(9·3%)

(Interview responses were not always complete hence varying denominator for some characteristics)
SD standard deviation; IQR inter quartile range
**WHO Global Database on Child Growth and Malnutrition (data incomplete – no age/ weight z score for > 10 year olds)*
+ trauma: road traffic accidents(29), burns (8) and other (6) non road traffic accident injury
++cardiac: congenital heart disease (17) and myocarditis/ cardiomyopathy (13)
*** neurology includes meningitis (14), epilepsy(3);*
 # respiratory: infective (pneumonia/bronchiolitis) (82); obstructive airway/croup/asthma (13)
sepsis/ septic shock: neonatal (18), older infants/ children (24)
****other includes: surgical (12),death unknown causes (7), overdose (3), drowning (2), renal failure, diabetic keto-acidosis, hepatic failure*
[x] HIV status where child (or mother) was tested and result available

Table 4-2 Medical patient's diagnosis and age grouping

Primary PICU/ Final Diagnosis	Age at PICU Admission/ Death (months)					Total (% of all medical cases)
	< 1 month	1 month - 1 year	1 – 2 years	2 – 5 years	> 5 years	
Pulmonary infective: Pneumonia unspecified (43); pneumonia viral (29); bronchiolitis (5); pneumonia aspiration (2); PCP (2); TB (1)	2	69	6	4	1	82 (34.3%)
Sepsis/ septic shock	19	17	2	1	3	42 (17.6%)
Neurology: meningitis (14)/ epilepsy (3)	0	4	3	7	6	20 (8.4%)
Pulmonary - airway obstruction: Asthma (5)/ croup (4)/ stridor (8)/ foreign body aspiration (3)	1	6	3	5	5	20 (8.4%)
Cardiac - congenital	2	13	1	1	0	17 (7.1%)
Cardiac other: myocarditis/ cardiomyopathy	1	3	3	3	3	13 (5.4%)
Gastro-enteritis	0	9	4	0	0	13 (5.4%)
Surgical: appendicitis/ bowel infarct/ NEC/ *etc.*	4	3	0	4	1	12 (5.0%)
Misc: overdose (3); drowning (2); renal failure; diabetic keto-acidosis; hepatic failure	1	3	3	4	2	13 (5.4%)
Unknown (death prior to diagnosis)	0	5	0	1	1	7 (2.9%)
TOTAL (% of all medical cases)	**30 (12.6%)**	**132 (55.2%)**	**25 (10.5%)**	**30 (12.6%)**	**22 (9.2%)**	**239**

PICU paediatric intensive care unit; PCP Pneumocystis pneumonia; TB tuberculosis; NEC necrotising enterocolitis

4.2.1.2 *Trauma Cases*

Trauma cases were predominantly (65.1%) a result of motor vehicle accidents (MVAs) (of which eight cases were passengers and 20 pedestrians) and occurred in older children. There were more burns in the toddler age group, shown in Table 4-3.

Table 4-3 Trauma Aetiology/ Diagnosis by Age Group

Primary PICU/ Final Diagnosis	Age PICU Adm/ Death (months)					Total (% of all trauma cases)
	< 1 month	1 month - 1 year	1- 2 years	2- 5 years	>5 years	
Motor Vehicle Accident		3	3	7	15	28 (65.1%)
• **MVA primary head injury**	0	3	2	5	7	17 (40.0%)
• **MVA polytrauma**	0	0	1	2	8	11 (25.6%)
Non Motor Vehicle Related						
Burn: inhalational (5); multiple (2)	0	0	4	1	3	8 (18.6%)
Gunshot Wound: single head wound (2); multiple (1)					3	3 (7.6%)
Trauma other: skull fracture (NAI) (2); caustic oesophagitis; spondylosthesis	0	2	0	1	1	4 (9.3%)
TOTAL TRAUMA (%)	0 (0%)	5 (11.6%)	7 (16.3%)	9 (20.9%)	22 (51.2%)	43

PICU paediatric intensive care unit; MVA motor vehicle accident; NAI non accidental injury

4.2.2 Diagnosis by Age and Time of Year

Table 4-4 describes the diagnostic groups by age group. Although there is overlap of the infectious causes in several categories (sepsis, pulmonary infective, as well as pulmonary obstructive that included croup) which blurs the classifications. It can be seen that sepsis both in the neonatal and infant groups, is important, as well as pneumonia in infants, both having frequent PICU admissions. Of further interest is the seasonal variation in disease, and it is clear that respiratory illness is more frequent in the winter months (May – September) but does occur throughout the year, and there were no other clear trends (Figure 4-1 and Figure 4-2).

Table 4-4 Principal diagnosis and age group of enrolled children

Diagnostic group	< 1 month		1 month - 1 year		1- 5 years		> 5 years		Total	
	Count	%	Count	%	Count	%	Count	%	Count	%
Trauma	0	0.0%	5	3.6%	16	22.5%	22	50.0%	43	15.2%
Cardiac	3	10.0%	16	11.7%	8	11.3%	3	6.8%	30	10.6%
Gastro-enteritis	0	0.0%	9	6.6%	4	5.6%	0	0.0%	13	4.6%
Neurological	0	0.0%	4	2.9%	10	14.1%	6	13.6%	20	7.1%
Pulmonary Obstr	1	5.0%	6	4.4%	8	11.3%	5	11.4%	20	7.1%
Pulm Infective	2	2.4%	69	50.4%	10	14.1%	1	2.3%	82	29.1%
Sepsis	19	45.2%	17	12.4%	3	4.2%	3	6.8%	42	14.9%
Other	5	15.6%	11	8.0%	12	16.9%	4	9.1%	32	11.3%
Total	30	100.0%	137	100.0%	71	100.0%	44	100.0%	282	100.0%

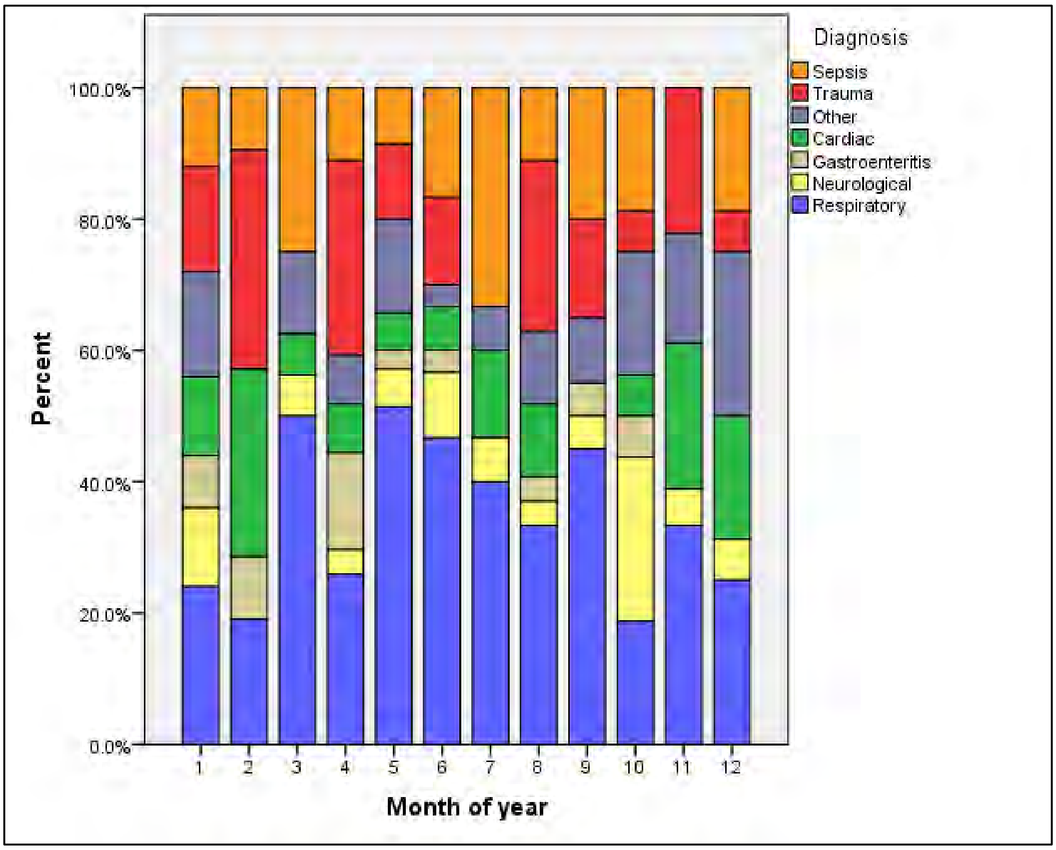


Figure 4-1 Monthly Diagnosis Proportions for the year of data collection

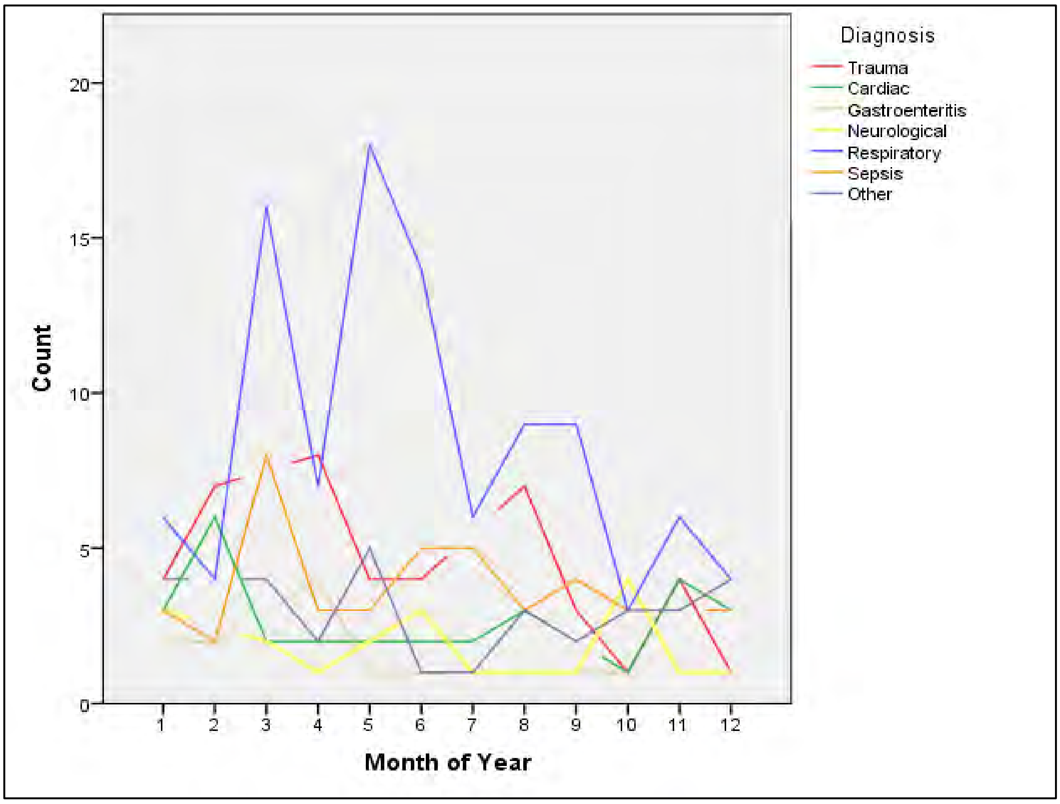


Figure 4-2 Diagnosis spread across the year of data collection

4.3 ACCESS TO CARE ISSUES

Most children (254, 90·1%) lived within the Cape Town metropol. Caregivers were asked about the nearest health facilities to their home and reported that the nearest facility was a mean of two km from the home (range, 0-30km) and the nearest 24 hour facility was six km away (range, 0-60km) as shown in Table 4-5. This is particularly pertinent in the light of transport to the nearest facility being on foot for 72.6%, and to the nearest 24 hour facility via public transport in 70.3% of cases. Few caregivers called for an ambulance from home for a medical problem (15.9 %), although more (58.1%) used an ambulance from the scene of a trauma incident. A quarter (26.2%) of caregivers knew the correct EMS emergency phone number, with many claiming it would take too long for EMS to come or EMS would not come to their homes in informal settlements. A quarter of parents disclosed consulting elsewhere prior to the acute episode (which may have been another health facility/ practitioner or a traditional healer).

Medical patients had a median interval of two days (range, 0 – 66 days) from reported first onset of illness until presentation to the health care system, with more than half (55.8 %) judged by the panel to have delayed seeking health care for the acute illness. The reported delay from onset of injury was less than a day for the vast majority (41 (95.3 %) of trauma patients.

Table 4-5 Access to care issues

		Medical (n=239)		Trauma (n=43)		Total (n=282)	
Issues with prevention of disease/injury?#	No	132	63.8%	1	2.5%	133	53.8%
	Yes	75	36.2%	39	97.5%	114	46.2%
Knowledge of danger signs?#	No	104	45.4%	4	20.0%	108	43.4%
	Yes	125	54.6%	16	80.0%	141	56.6%
Delay: onset illness to first presentation (days)	< 1 day	67	28.0%	41	95.3%	108	38.3%
	1 - 2 days	55	23.0%	1	2.3%	56	19.9%
	2 - 3 days	36	15.1%	0	0.0%	36	12.8%
	> 3 days	81	33.9%	1	2.3%	82	29.1%
Delay in seeking healthcare?#	No	102	44.2%	29	87.9%	131	49.6%
	Yes	129	55.8%	4	12.1%	133	50.4%
Consultation for this acute episode elsewhere (prior to this pathway)?	No	154	74.8%	22	100.0%	176	77.2%
	Yes	52	25.2%	0	0.0%	52	22.8%
Distance to nearest facility (km)	*Mean (range)*	2 (0-30)		1 (0-15)		2 (0-30)	
Usual means of transport to nearest facility	Walking					199	72.6%
	Taxi					57	20.8%
	Private Car					12	4.4%
	Other					6	2.2%
Distance to nearest 24 hr facility	*Mean (range)*	6 (0-60)		7(0-30)		6 (0-60)	
Usual means of transport to nearest 24 hour facility	Walking					31	14.2%
	Taxi					154	70.3%
	Private Car					25	11.4%
	Other					9	4.1%
Appropriate use of EMS?#	No	181	81.2%	17	41.5%	198	75.0%
	Yes	42	18.8%	24	58.5%	66	25.0%
Action from parent for very sick child	Phone ambulance					85	30.1%
	Go to neighbor					58	20.6%
	Private Car to facility					61	21.6%
	Other*					76	
Action from parent for severely injured child	Phone ambulance					141	50.0%
	Go to neighbor					38	13.5%
	Private Car to facility					50	17.7%
	Other*					53	
Knowledge of correct emergency phone number	Yes (10177/ 107/ 112/ 082 911/ 10111)					74	26.2%

 # as judged by reviewers

**other: walk, hire private taxi, family vehicle, don't know*

4.4 DISCUSSION: DEMOGRAPHICS; DIAGNOSIS AND ACCESS TO CARE

4.4.1 General and Recruitment Process

Demographics

The cohort demographics were compared to the 2011 census figures for the Western Cape[60] in Table 4-6. The cohort was much poorer than the province population with greater unemployment levels (although mothers of young children are more likely to be unemployed) and a far greater proportion living in informal dwellings (44.7% *vs* 22%). Income for the cohort was self-reported, and possibly under-reported (patients are charged for public sector hospital services on a scale according to income so it is likely parents understate their income to anyone related to the hospital) , and a higher HIV prevalence than the province overall. This is unsurprising given that the census includes all socio-economic sectors of Cape Town, while only the poorer (and those requiring highly specialized management) would tend to use the public health sector. Access to amenities was similar to the 2011 census population statistics for Western Cape, but ownership of some expensive assets such as satellite dish, computer and motor vehicle was lower.

Child Gauge[43] also provides some population demographics for the Western Cape, which paint a more positive picture than the census data does. These data show that 16% of Western Cape children are living in informal housing, 22% in overcrowded households (more than two people per room); 95% have water on site; and 94% sanitation on site. Comparison with these data would suggest an even greater inequity between the PTC cohort and the overall provincial data.

Both datasets highlight the increased risk of adverse health outcomes in impoverished communities. These data are representative of the RCWMCH emergency PICU admission population – showing a similar distribution of demographics, outcomes and severity and spread evenly over a full year period.

Table 4-6 Comparison of Pathways to Care cohort to Western Cape population

Indicator	Pathways to Care Cases	Western Cape (2011)#
% living in informal dwellings	44·7	22·0
Household Annual Income	85·2% < R60 000 66·4% < R30 000	Mean R 143 000
Child Support Grant	53%	38·1%
Single parent	58%	-
Mother's age	Mean 28·9 (SD 6·9)	-
Maternal Unemployment rate	65·6%	21·4%
Mother's schooling Grade 11-12 or higher	53%	43%
Father's age	Mean 33·0 (SD 8·5)	-
Father's unemployment rate	24·5%	21·4%
Father's highest schooling	49% Grade 11-12 or higher	43%
Both parents unemployed	50/282 (17·7%)	11%
Amenities		
Cooking – electric	89·4%	86·9%
Heating – electric	65·2%	63·5%
Lighting – electric	91·5%	93·4%
Water – on site	74·8%	88·4%
Sanitation – toilet on site	86·1%	92·0%
Assets **Radio**	63·5%	69·2%
Television	88·3%	85·5%
Satellite Dish	17·4%	30·6%
Fridge	74·1%	80·5%
Stove	93·6%	90·2%
Washing Machine	37·2%	57·6%
Motor Vehicle	17%	43·6%
Cellular Phone	91·5%	88·9%
Computer	12·4%	34·4%
Distance to nearest health facility	3·5 km (SD 6·4)	14% > 30 minutes away
Distance to nearest 24hr facility	10·5 km (SD 17·5)	-
Means of transport	71% walk, 22% taxi	-

 # South African Child Gauge 2013.[43] *; Statistics South Africa. Census 2011 Municipal Report Western Cape.*[60]

Diagnosis

The medical patients were predominantly infants under a year of age, and included a high proportion that were underweight for age (probably further skewed by low birth weight (LBW)). This potentially provides a focus for preventative interventions, and certainly provides insight into the particular clinical skills that may require upgrading for healthcare workers. In addition it provides data to support increased healthcare support for LBW infants.

Classifying each child into a diagnostic group was not always clear, even retrospectively. There were children who presented initially with apparently simple respiratory or gastro-enteritis signs and symptoms, who by the time of PICU admission were in septic shock, whether through disease progression in the interim, or misdiagnosis initially. The "respiratory" group which was the largest group, was separated into “pulmonary infective” being pneumonia (viral or bacterial) and “pulmonary obstructive” being a mixture of croup (although infective), asthma and upper airway obstruction which may not be an entirely usual grouping, but allowed for some separation of the large pneumonia group. Although the final diagnoses were dominated by infections, the prevalence of HIV infection was low (despite the 34.6% perinatal exposure to HIV in the cohort), perhaps reflecting the success of an effective programme to limit mother to child transmission of HIV infection. The definition of final diagnosis was sometimes complex as patients may have changed (*e.g*. a child initially presented with pneumonia but by the time of PICU admission was in septic shock) or in children with multiple pathologies there may have been diverse clinical opinions regarding the predominant reasons for PICU admission. This often “blurred” definition around the different and evolving presentations of infectious diseases and sepsis is perhaps an important concept which should be borne in mind for the education of health care workers, such as in delineating universal danger signs which require attention and management, rather than around specific disease entities.

Gastro-enteritis is a significant problem in LMIC as well as in Cape Town. Although as a presenting problem it may be associated with many conditions, such as septic shock, as a primary pathology from viral infection it is a well-documented issue in Cape Town with a “gastro season” in late summer which has the propensity to overwhelm health facilities at times.[254] The 2011/2012 “gastro season” did not seem to be a particularly severe one, although this and the low numbers of gastro-enteritis patients who reached PICU may be a reflection of the high intensity program implemented in the Western Cape, educating, providing clear algorithms and management criteria and supporting early PHC response to children presenting with diarrhoea.[89] It is however commendable just how few children with diarrhoea reached the PICU and one of the positive findings of the study.

The RCWMCH is the provincial referrals centre for paediatric cardiology and cardiac surgery hence the high number of cardiac admissions to PICU, many from outside the immediate metropolitan area.

Access to Care

In office hours, caregivers reported distances and access to healthcare facilities seem reasonable within the Cape Town metropol. After hours there is a real access problem to many parents, particularly in areas where it may be unsafe to move around at night. This likely influenced the decision by parents of children who become sick in the night (or are first noticed to be sick at night, which is a common scenario with working parents who only see their children in the late afternoon/ evening) to either wait for morning, or in extreme situations to look for transport and help at night. Given that most families did not have access to private transport (either their own vehicle or a family member/ neighbour with their own vehicle), the distance to after-hours healthcare facilities (by far the most common site for acute presentations) reveals a significant challenge to improving access to emergency healthcare for this group, and not readily comparable to international standards for distance to health care facilities due to the transport barriers. The majority of patients came from Xhosa-speaking families which may contribute to problems in communication as the profile of healthcare workers in the Western Cape still has a predominance of Afrikaans and English speakers.

Interview data from the caregivers show there were many undocumented barriers to accessing appropriate emergency care, from facilities which are only open in office hours, facilities which only see a predetermined number of “first come, first served” patients in a day, navigating through security guards and administrative staff, and communicating the severity of a child's condition to staff members. Further qualitative analysis of these data will elucidate more of the details and patterns.

The data suggest underutilization of emergency services for paediatric primary (from home or scene) cases, in line with international trends.[124-127] In addition parents were unclear on where to take a sick or injured child and if they did decide to use EMS, how to call[124-127] them. There was a perception that EMS was too slow and under-resourced and would never come to the house for a sick child. However, objective data demonstrate that EMS resources and responses times are actually good and close to international standards in the urban areas of Cape Town, however but this is likely a recent phenomenon.[255-257](personal communication L. Wallis, 2014) Another real concern in informal areas without clear street markings was that EMS would not find the address, hence the practice by some parents of calling for EMS from a police station or central point. Marketing and informing the public (and particularly caregivers of high risk and young babies) about how and when to access EMS and the emergency services at their local facilities may be a high impact and relatively simple intervention highlighted by these findings.

Summary

In summary, data was collected on a sample of children thought to be representative of the population served by the RCWMCH, and the population of the Western Cape who use public health facilities. Families enrolled in the study were predominantly poor and living in informal or semi-formal housing in Cape Town, Those admitted to PICU were predominantly infants with medical problems (largely infective), as well as a range of other conditions including trauma which were representative of the spread of critical illness encountered in the city. The study enrolled children consistently over the year-long study period to control for any seasonal variations. There were significant access issues for parents of critically ill children, despite the apparent density of health facilities in the city, particularly after hours. Whether from past experience or beliefs, caregivers were reticent to call an ambulance to the home of a sick child, especially at night, and chose to either wait until the following day, or if it seemed urgent to beg or borrow some form of transport to get to the nearest open health facility.

5 OUTCOME AND QUALITY ASSESMENT

Measuring the quality and the effectiveness of an entire system and complex pathway involving a multiple (and variable) number of steps for each patient is a challenge. Objective outcomes relate only to the final outcome of the patient and a measure of their physiological severity on admission to PICU. Other assessments are based on the expert panel consensus gradings for the various aspects of care, and on the parent/ caregiver perceptions and impressions of the care delivered.

5.1 OUTCOME OBJECTIVE

For PICU admissions only:

On admission to PICU, there was no significant difference between the predicted risk of mortality for the trauma (PIM2 median 7·6%) and medical (PIM2 median 6·9%) cases (p=0·375). Total RCWMCH length of stay was longer for the trauma cases (median 15·0 days (IQR 9·8-25·8) than for medical (10·5, 7·0-20·0) (Table 5-1). By 30 days, almost two-thirds of the children had been discharged (163, 64·7%), a quarter remained in hospital (61, 24·2%) and the remainder had died (28, 11·1%).

Table 5-1 Objective outcomes of children admitted to the Paediatric Intensive Care Unit

	Medical **(n=218)**	Trauma **(n=34)**	Total **(n=252)**
Outcome at 30 days			
Death in/after PICU	26(11·9%)	2(5·9%)	28(11·1%)
Discharge home	150(68·8%)	13(38·2%)	163(64·7%)
Remain inpatient	42(19·3%)	19(55·9%)	61(24·2%)
	Median (IQR)	**Median (IQR)**	**Median (IQR)**
Risk of mortality* (PIM2 %)	6·9(1·8-18·2)	7·6(4·6- 12·6)	6·9(2·0-16·6)
PICU Length of stay (hours)	73·6 (43·0-159·4)	94·5 (43·6-218·7)	76·9 (43·0-164·0)
Total RCWMCH Length of stay (days)	10·5(7·0-20·0)	15·0(9·8-25·8)	11·0 (7·0-21·0)

** On admission to PICU*
IQR inter quartile range; PIM2 score – Paediatric Index of Mortality 2 [13]; PICU Paediatric Intensive Care Unit; RCWMCH Red Cross War Memorial Children's Hospital

A more detailed analysis of the outcomes for the different groups of patients is shown in Table 5-2. More than half the trauma admissions were still in hospital (not necessarily at RCWMCH) a month later. A substantial number of deaths occurred in the cardiac, neurological, sepsis and "other" groups, but few in the remainder. On the positive side, the majority of gastro-enteritis and respiratory cases had been discharged home.

Risk of mortality on arrival at PICU was highest for the cardiac patients, as was their length of stay in PICU and RCWMCH (Table 5-3). Lowest risk was for respiratory cases, predominantly admitted to PICU for mechanical ventilator support of some kind, although some of the pneumonia patients had a relatively long stay in PICU.

Table 5-2 Thirty day outcomes for all children admitted to PICU according to main diagnosis

	Total (PICU Admissions)		Discharge Home		Remain inpatient		Death in/ after PICU	
	Count	*Column %*	Count	Row N %	Count	Row N %	Count	Row N %
Trauma	*34*	*13.5%*	13	38.2%	19	55.9%	2	5.9%
Cardiac	*27*	*10.7%*	15	55.6%	7	25.9%	5	18.5%
Gastro-enteritis	*11*	*4.4%*	11	100.0%	0	0.0%	0	0.0%
Neurological	*20*	*7.9%*	10	50.0%	6	30.0%	4	20.0%
Pulmonary Obstr	*19*	*7.5%*	15	78.9%	4	21.1%	0	0.0%
Pulm Infective	*78*	*31.0%*	58	74.4%	15	19.2%	5	6.4%
Sepsis	*38*	*15.1%*	25	65.8%	6	15.8%	7	18.4%
Other	*25*	*9.9%*	16	64.0%	4	16.0%	5	20.0%
Total	***252***	***100.0%***	**163**	**64.7%**	**61**	**24.2%**	**28**	**11.1%**

PICU paediatric intensive care unit; neurology includes meningitis , epilepsy; respiratory infective (pneumonia/bronchiolitis); respiratory obstructive (airway/croup/asthma); sepsis/ septic shock; other includes: surgical, death unknown causes, overdose, drowning, renal failure, diabetic keto-acidosis, hepatic failure

Table 5-3 Objective Outcomes for PICU admissions by main diagnosis

		Risk of Mortality (PIM2%)			PICU LOS (hrs)			RCWMCH LOS (days)		
	Count	Median	Percentile 25	Percentile 75	Median	Percentile 25	Percentile 75	Median	Percentile 25	Percentile 75
Trauma	34	7.6	4.6	12.6	94.5	45.5	215.5	15	10	25
Cardiac	27	17.0	6.4	34.3	171.2	70.0	308.5	19	12	28
Gastro-enteritis	11	6.7	2.2	16.5	36.3	26.5	78.0	9	7	9
Neurological	20	2.4	1.1	7.3	64.5	36.0	96.4	11	5	27
Pulmonary Obstr	19	1.5	0.0	7.3	57.7	25.3	117.3	8	4	15
Pulm Infective	78	3.0	1.2	9.7	108.8	52.6	176.5	11	7	20
Sepsis	38	9.4	5.8	33.6	61.6	37.0	96.3	7	6	15
Other	25	12.1	8.4	22.7	45.6	39.8	104.2	10	5	17
Total	**252**	**6.9**	**2.0**	**16.6**	**76.9**	**43.0**	**163.9**	**11**	**7**	**21**

PICU paediatric intensive care unit; neurology includes meningitis , epilepsy; respiratory infective (pneumonia/bronchiolitis); respiratory obstructive (airway/croup/asthma); sepsis/ septic shock; other includes: surgical, death unknown causes, overdose, drowning, renal failure, diabetic keto-acidosis, hepatic failure

5.2 EXPERT REVIEWER ASSESSMENT

The global quality of care was graded good in only 29 (10·3%) of all cases, with the majority graded as fair (196, 69·5%) (Table 5-4). For those admitted to PICU, admission was considered avoidable or potentially avoidable for 61 (24·2%), and the severity of illness/injury on admission was considered avoidable or potentially avoidable in 185 (73·5%). Half (141, 50·0%) of all cases had at least one modifiable factor which had a major impact in their pathway, whilst the majority (267, 94·7%) had at least one moderate impact factor (Table 5-4, Figure 5-1). Three quarters of cases (210, 74·5%) had clear or likely health system issues, defined as health system issues prior to the acute episode which may have averted or influenced the acute healthcare episode.

Table 5-4 Outcomes of expert clinical review

	Medical (n=239)	Trauma (n=43)	Total (n=282)
Global Quality of Care*			
Poor	55(23·0%)	2(4·7%)	57(20·2%)
Fair	166(69·5%)	30(69·8%)	196(69·5%)
Good	18(7·5%)	11(25·6%)	29(10·3%)
Avoidability of Death	(n=21)	(n=9)	(n=30)
Not Avoidable	6(28·6%)	7(77·8%)	13(43·3%)
Potentially Avoidable	12(57·1%)	2(22·2%)	14(46·7%)
Avoidable	3(14·3%)	0(0·0%)	3(10·0%)
Avoidability of PICU	(n=218)	(n=34)	(n=252)
Not Avoidable	161(73·9%)	30(88·2%)	191(75·8%)
Potentially Avoidable	52(23·9%)	4(11·8%)	56(22·2%)
Avoidable	5(2·3%)	0(0·0%)	5(2·0%)
Avoidability of Severity	(n=218)	(n=34)	(n=252)
Not Avoidable	49(22·5%)	18(52·9%)	67(26·6%)
Potentially Avoidable	155(71·1%)	15(44·1%)	170(67·5%)
Avoidable	14(6·4%)	1(2·9%)	15(6·0%)
Number of Modifiable Factors! median (range; IQR)			
Major Impact	1 (0-16; 0-3)	0 (0-8; 0-1)	1 (0-16; 0-3)
Moderate Impact	6 (0-19; 4-10)	5 (0-13; 3-8)	6 (0-19; 3-9)
System Issues#			
No	36(15·1%)	36(83·7%)	72(25·5%)
Possibly	72(30·1%)	3(7·0%)	75(26·6%)
Yes	131(54·8%)	4(9·3%)	135(47·9%)

IQR inter quartile range; PICU Paediatric Intensive Care Unit
** Grading of quality of care was performed relative to the expectations of reviewers: poor - health care which was clearly below the average expectations of the facility/health care provider (HCP); fair – health care of an average level expected of the facility/HCP; good – health care at an excellent level above average expectations*
! Grading of Modifiable Factors: major (clear negative impact on the outcome for the patient), moderate (minimal negative impact on the outcome but likely caused some morbidity and/or extended the illness duration)
(e.g. failure to administer a fluid bolus in a shocked child would be a major MF, delay in administration of antibiotics to a child with respiratory distress (of unclear aetiology) a moderate MF)
 # System Issues - defined as potential healthcare interventions prior to the acute episode which could have had a positive impact on the health of the child prior to the acute critical illness. (e.g. missing long term deterioration at a prior consultation or inadequate follow up of a high risk baby)

Figure 5-1 presents graphically the differences between medical and trauma cases in terms of avoidability (grouping avoidable and potentially avoidable together *vs* not avoidable), demonstrating that for medical cases severity, ICU admission and death were more often avoidable than for trauma cases.

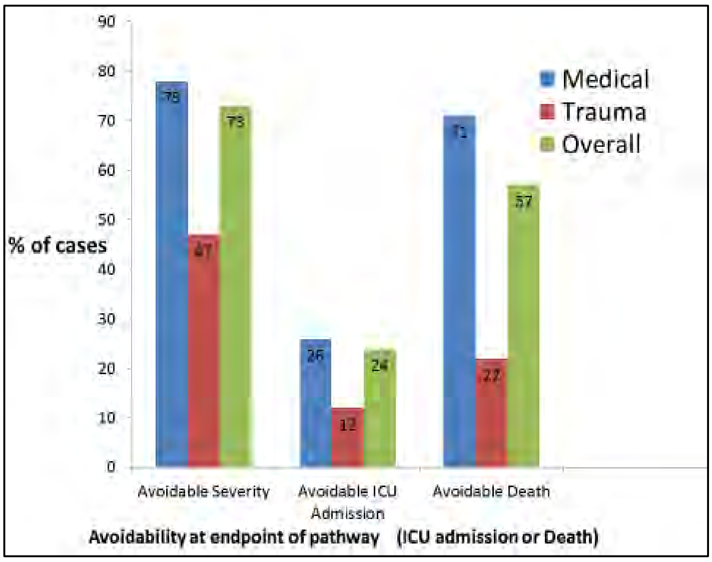


Figure 5-1 Avoidability of ICU admission or death for all cases

Looking at different diagnostic groups in Table 5-5 (which combines good and fair; avoidable and potentially avoidable to give a clearer binary grading and shows just the negative or adverse grading for simplicity), there do seem to be trends, although numbers are not high enough to show statistical significance. All the gastro-enteritis cases were thought to have had avoidable severity, and some system issues (and the two gastro-enteritis deaths were judged avoidable). Sepsis (composed of those patients with overwhelming sepsis or septic shock as the primary presentation at the time of PICU admission) likewise had a high proportion of avoidable severity and system issues, as well as over a third poor quality of care. System issues were identified as contributing to the problem in over 75% for all medical cases, but seldom for trauma cases.

Table 5-6 shows the same reviewer assessments for different age groups of children. Again numbers are too low to draw clear conclusions, although there seem to be more identified system errors in the infants and neonates.

Table 5-5 Adverse Reviewer Gradings for Each Diagnostic Group#

Diagnosis	Count	Global Care Assessment	Avoidability ICU	Avoidability Severity	System Issues	Avoidability of Death (n=30)	
		Poor	Avoidable	Avoidable	Yes/ possibly	Count	Avoidable
		% of cases	% of cases	% of cases	% of cases		% of cases
Trauma	43	5%	12%	47%	16%	9	22%
Cardiac	30	13%	4%	63%	90%	3	33%
Gastro-enteritis	13	31%	55%	100%	100%	2	100%
Neurological	20	45%	40%	85%	90%	0	0%
Pulmonary Obstr	20	10%	32%	63%	75%	1	100%
Pulm Infective	82	13%	22%	71%	82%	4	75%
Sepsis	42	38%	34%	92%	93%	4	100%
Other	32	28%	24%	88%	75%	7	57%
Total	282	20%	24%	73%	74%	30	57%

 # reviewer gradings have been simplified into a binary assessment (i.e. poor vs fair and good; avoidable and potentially avoidable vs not avoidable) and the percentage of the adverse assessment (i.e. poor or avoidable) for each diagnostic group is given. (e.g. top left – 5% of trauma patients had an assessment of poor global care assessment (and thus 95% were fair/ good); and 12% of trauma patients had an avoidable (or potentially avoidable) PICU admission (thus 88% were not avoidable)
(colour coded - green = good assessment/ outcome, red = poor)

Table 5-6 Reviewer Grading for each age group of cases

		Count	Global Care Assessment	Avoidability ICU	Avoidability Severity	System Issues	Avoidability of Death (n=30)	
			Poor	Avoidable	Avoidable	Yes/ poss	Avoidable	
			% of cases	% of cases	% of cases	% of cases		% of cases
Age PICU Adm/ Death (months)	< 1 month	30	27%	24%	86%	90%	1	100%
	1 month - 1 year	137	19%	25%	73%	86%	16	50%
	1yr - 2yr	32	6%	32%	79%	63%	4	75%
	2yr - 5yr	39	31%	29%	82%	64%	1	100%
	> 5 yr	44	20%	11%	53%	45%	8	50%

 # reviewer gradings have been simplified into a binary assessment (i.e. poor vs fair and good; avoidable and potentially avoidable vs not avoidable) and the percentage of the adverse assessment (i.e. poor or avoidable) for each age group is given.
(colour coded - green = good assessment/ outcome, red = poor)

5.2.1 Facility and EMS Review

The quality of care at each facility level across all consultations, as assessed by the clinical reviewers revealed that between 29% and 51% of contacts at primary care facilities were considered fair or good, and this increased to 73% to 94% at the hospital based settings (Table 5-7).

Table 5-7 Details of Facilities relative to Quality of Care

		N=	Poor		Fair		Good		*Panel Disagree*	
			Count	Row N %	Count	Row N %	Count	Row N %	*Count*	*Row N %*
Facilities Overall		612	125	20.4%	334	54.7%	95	15.5%	*57*	*9.3%*
Medical		533	117	22.0%	293	55.0%	79	14.8%	*44*	*8.3%*
Trauma		78	8	10.3%	41	52.6%	16	20.5%	*13*	*16.7%*
Level of Facility	GP	21	14	66.7%	6	28.6%	0	0.0%	*1*	*4.8%*
	CHC 24hr	106	41	38.7%	47	44.3%	9	8.5%	*9*	*8.5%*
	Clinic	53	20	37.7%	27	50.9%	1	1.9%	*5*	*9.4%*
	District Hospital	45	9	20.0%	22	48.9%	11	24.4%	*3*	*6.7%*
	Regional Hospital	50	2	4.0%	31	62.0%	16	32.0%	*1*	*2.0%*
	Private Hospital	11	1	9.1%	7	63.6%	1	9.1%	*2*	*18.2%*
	RCWMCH EC	239	25	10.5%	140	58.6%	47	19.7%	*27*	*11.3%*
	RCWMCH Ward	75	11	14.7%	49	65.3%	7	9.3%	*8*	*10.7%*
	Other	11	2	18.2%	5	45.5%	3	27.3%	*1*	*9.1%*
Facility Triage Colour#	Green	4	1	25.0%	2	50.0%	1	25.0%	*0*	*0.0%*
	Yellow	16	4	25.0%	11	68.8%	1	6.3%	*0*	*0.0%*
	Orange	98	33	33.7%	49	50.0%	6	6.1%	*10*	*10.2%*
	Red	163	21	12.9%	94	57.7%	34	20.9%	*14*	*8.6%*
Timing of first presentation	Office hours	199	39	19.6%	104	52.3%	33	16.6%	*23*	*11.6%*
	After hours	400	82	20.5%	224	56.0%	61	15.3%	*33*	*8.3%*

GP general practice; CHC 24 hour community health centre; RCWMCH Red Cross War Memorial Children's Hospital; EC emergency centre; other (operating theatre, private sector, tertiary hospital, midwife obstetric unit, community day centre)
 # triage according to South African Triage Score: Red most urgent; green least urgent

Table 5-8 gives the data for EMS transfers, which were largely judged more positively than the facility visits, with between 64% and 92% fair of good across types of transfers. Interfacility transfers, although the commonest, were judged as poor in 29% of transfers, but when an ALS practitioner was present the transfer was rated better (12% poor). Trauma cases, and PFS transfers were judged most positively, with 42% and 44% of contacts respectively being rated as good.

Table 5-8 Details of EMS transfers relative to Quality of Care

			Poor		Fair		Good		Panel Disagree	
		N=	Count	Row N %	Count	Row N %	Count	Row N %	Count	Row N %
EMS Overall (n=290)		290	56	19.3%	137	47.2%	73	25.2%	*24*	*8.3%*
EMS Call Type	Scene	32	1	3.1%	15	46.9%	12	37.5%	*4*	*12.5%*
	Home	33	2	6.1%	21	63.6%	6	18.2%	*4*	*12.1%*
	Inter-facility	168	48	28.6%	74	44.0%	34	20.2%	*12*	*7.1%*
	PFS	43	3	7.0%	21	48.8%	18	41.9%	*1*	*2.3%*
	Flight	14	2	14.3%	6	42.9%	3	21.4%	*3*	*21.4%*
	Primary	67	3	4.5%	37	55.2%	19	28.4%	*8*	*11.9%*
	Secondary	223	53	23.8%	100	44.8%	54	24.2%	*16*	*7.2%*
Highest Crew Qualification	BLS	42	13	31.0%	25	59.5%	0	0.0%	*4*	*9.5%*
	ILS	58	12	20.7%	34	58.6%	7	12.1%	*5*	*8.6%*
	ALS	144	17	11.8%	60	41.7%	57	39.6%	*10*	*6.9%*
	Dr	6	1	16.7%	3	50.0%	1	16.7%	*1*	*16.7%*
Medical or Trauma	Medical	238	52	21.8%	119	50.0%	50	21.0%	*17*	*712%*
	Trauma	52	4	7.7%	18	34.6%	23	44.2%	*7*	*13.5%*
Priority*	P1	156	23	14.7%	74	47.4%	45	28.8%	*14*	*9.0%*
	P2	83	22	26.5%	42	50.6%	15	18.1%	*4*	*4.8%*
Triage Colour#	Green	11	4	36.4%	6	54.5%	0	0.0%	*1*	*9.1%*
	Yellow	24	8	33.3%	13	54.2%	1	4.2%	*2*	*8.3%*
	Orange	70	13	18.6%	39	55.7%	14	20.0%	*4*	*5.7%*
	Red	124	15	12.1%	53	42.7%	45	36.3%	*11*	*8.9%*

EMS emergency medical services; PFS paediatric flying squad, BLS basic life support, ILS intermediate life support; ALS advanced life support; Dr doctor

**EMS call are prioritized by the dispatch centre – P1 is urgent and the target is a response time of 15 minutes, P2 is the next group with target of < 30 minutes.*

 # triage according to South African Triage Score: Red most urgent; green least urgent

5.2.2 Consensus

Consensus was reached spontaneously (*i.e.* without a meeting) in just 55 (19.5 %) of cases, with the remaining 227 discussed at bi-weekly consensus meetings and usually fairly rapidly resolved as one reviewer or the other explained the rationale for their assessment. Of note consensus was only sought and achieved for the 4 "key" outcomes: overall quality of care; and avoidability of death/ PICU admission/ severity. Table 5-9 details cases where there was internal disagreement requiring consensus meeting discussion for each review issue. Figure 5-2 gives a visual representation of the reviewer grading for the main outcomes prior to consensus meeting.

The external review process began with all of the first 10 cases reviewed, and then another 27 cases making up 13.1% of the cases (35 PICU admissions, 2 deaths). Agreement between the internal consensus and external reviewer was reached in 6 (16%) of cases, with most disagreement being around global quality of care as shown in Table 5-9.

Table 5-9 Cases where there was disagreement requiring consensus meeting discussion for each of the four key outcomes

Review Issue	All cases n=	Internal algorithm disagreement requiring discussion at consensus meeting (n (%))	Externally Reviewed Cases n=	External Disagreement (to Internal Consensus) (according to algorithm)
Global QOC	282	12 (4.3%)	37 cases	6 (16.2%)
Avoidability Death	30	11 (36.7%)	2	0
Avoidability ICU	252	94 (37.3%)	35	9 (25.7%)
Avoidability Severity	252	135 (53.6%)	34	11 (32.4%)

QOC quality of care; ICU intensive care

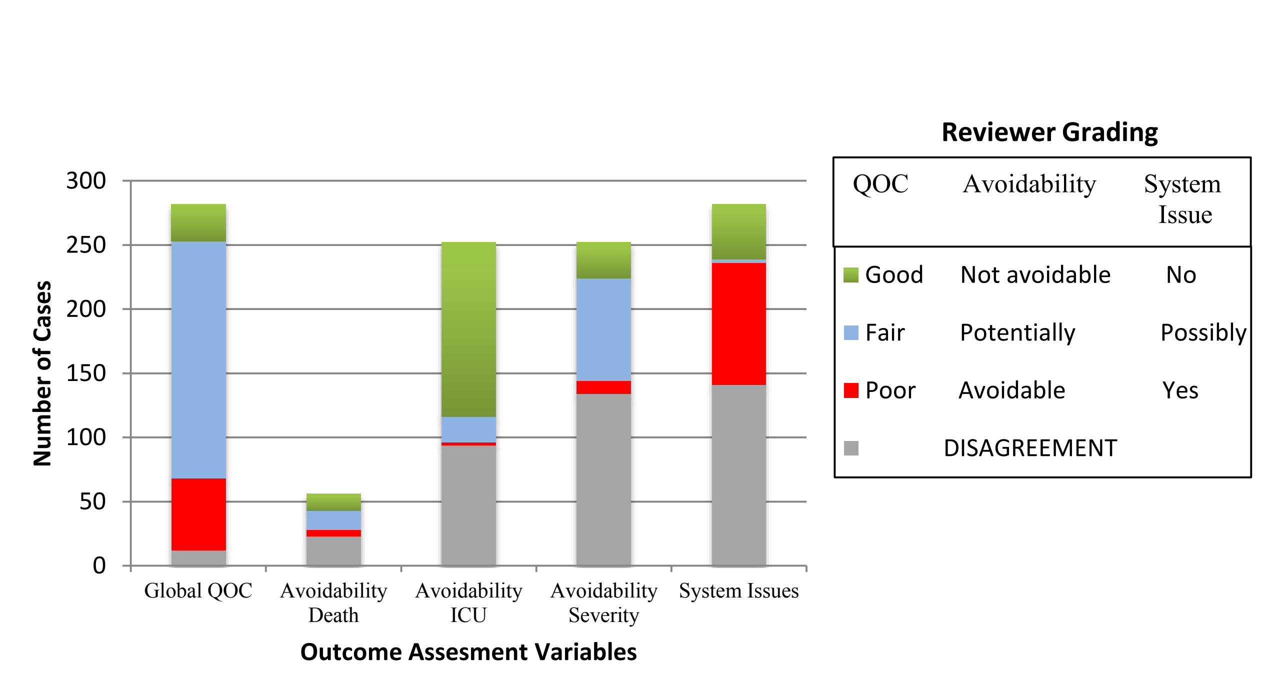


Figure 5-2 Internal Review Gradings prior to Consensus Meetings

Figure 5-3 shows consensus reviewer assessment for global quality of care through the calendar year of data collection (starting 1 November until 31 October). There is no clear change in reviewer assessment with time.

Agreement between the internal clinical reviewers and the final consensus (after discussion) for the four main outcomes (reduced to binary assessments, good and fair *vs* poor; and avoidable and potentially avoidable *vs* not avoidable) was moderate to substantial (Table 5-10) (kappa ranged from 0.454- 0.810).[245] The external reviewer generally rated care as better than the internal reviewers, with lower agreement with the consensus outcome (kappa ranged from 0.339 - 0.458; not estimable for avoidability of death (small numbers) and negative for Global quality of care (worse than chance)).

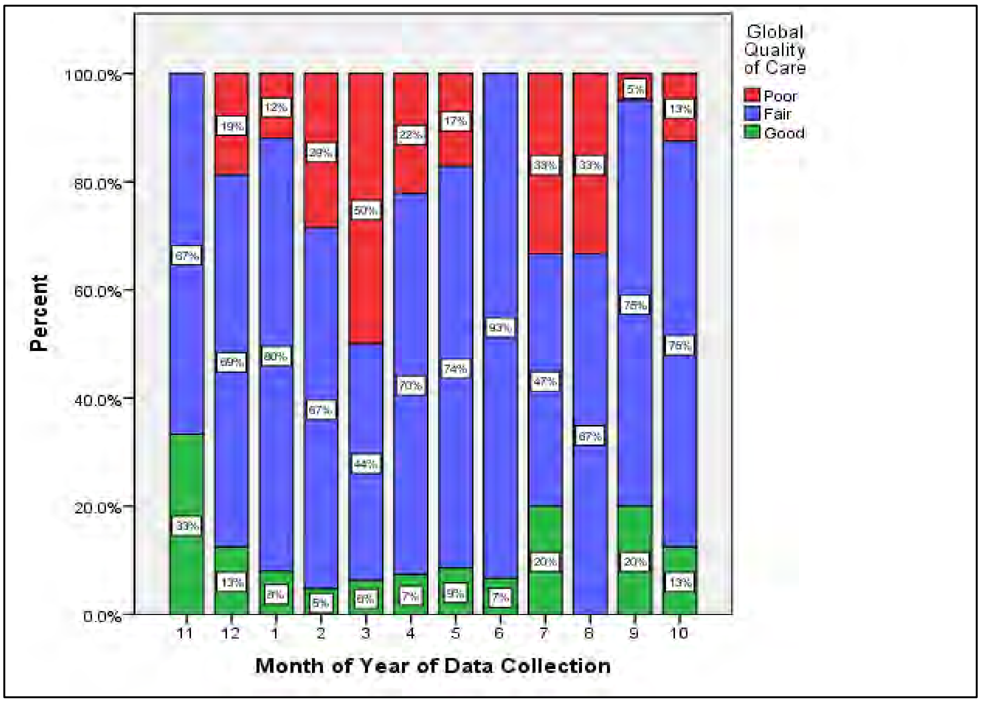


Figure 5-3 Consensus Gradings of Overall Quality of Care throughout the yearlong study period

Table 5-10 Kappa Scores for main review outcome variables (comparing each reviewer to consensus)

Outcome Variable	CF	PHC	EM	PICU	External*
Global QOC	0.562	0.519	0.579	0.500	-
Avoidability Death	0.723	0.586	0.646	0.810	-
Avoidability PICU	0.481	0.615	0.501	0.700	0.458
Avoidability Severity	0.386	0.454	0.454	0.523	0.339

In general, statistics ranging from 0.41 to 0.60 have been interpreted to indicate "moderate" agreement, those ranging from 0.61 to 0.80 have been interpreted to indicate "substantial" agreement, and those of >0.81 have been interpreted to indicate "near perfect" agreement (Landis, J. R., and Koch, G. G. The measurement of observer agreement for categorical data. Biometrics, 33: 159–174, 1977)
** There was no significance for the IM (external reviewer) correlations p>0.05*
QOC quality of care, PICU paediatric intensive care unit; CF clinical fellow; PHC primary health care reviewer; EM emergency medicine reviewer; PICU paediatric intensive care unit reviewer
All internal correlations were significant p<<0.005
CF – clinical fellow(PH), PHC primary health care reviewer(SR), EM emergency medicine reviewer(LW), PICU paediatric intensivist reviewer(AA), QOC quality of care, PICU paediatric intensive care

Appendix XIII gives a visual mapping of the consensus between reviewers for the main outcomes which makes it easier to assess the agreement between the panellists, in a non-quantitative way.

5.3 MULTIVARIABLE REGRESSION

Predictors of PICU outcomes were assessed for non-trauma cases (Table 5-11). (Trauma cases were seen as a separate entity, numbers were lower, and generally outcomes were better so they were not analysed further.) Children whose care pathway exhibited more major impact modifiable factors had a greater risk of mortality on admission to PICU (*p*=0.017), whereas cases with respiratory diagnosis (*p*=0.001) and longer duration from onset of illness to initial presentation at a healthcare facility (*p*=0.001) had a lower risk. Older children (*p*=0.022); those with a lower weight for age (z-score) (*p*=0.020) (i.e. more malnourished or premature); and those with a cardiac diagnosis (*p*=0.004) were likely to have a longer admission at RCWMCH.

Table 5-11 Clinical outcomes of multivariable linear regression for medical PICU admissions

Total n=218[a]	Beta	95% Confidence Interval		p
		Lower	Upper	
Outcome Risk of mortality on admission (PIM2)[b] (n=159)				(*significant (p< 0.05)
Gender[c]	0.545	-0.060	1.149	0.077
Age[c]	-0.039	-0.243	0.164	0.702
Weight for age[c]	-0.141	-0.302	0.020	0.086
Respiratory diagnosis	-1.143	-1.806	-0.480	0.001*
Number of major impact modifiable factors	0.154	0.027	0.280	0.017*
Delay onset of illness to first presentation	-0.541	-0.863	-0.218	0.001*
Outcome Length of Stay in RCWMCH (n=209)				
Gender[c]	0.028	-0.235	0.291	0.833
Age[c]	0.102	0.015	0.189	0.022*
Weight for age[c]	-0.078	-0.144	-0.012	0.020*
Cardiac diagnosis	0.576	0.183	0.968	0.004*
Outcome Length of Stay in PICU (n=213)				
Gender[c]	0.268	-0.040	0.576	0.088
Age[c]	-0.009	-0.113	0.095	0.869
Weight for age[c]	-0.054	-0.133	0.025	0.179

PICU Paediatric Intensive Care Unit; RCWMCH Red Cross War Memorial Children's Hospital, PIM2 score – Paediatric Index of Mortality
Gender, age, and expected weight for age (z-score) were entered into the linear regression analyses as fixed variables (regardless of association with the outcomes at univariate level). Additional demographic variables, diagnosis, pathway variables, and global assessment of care were entered into the regression analyses if there was a univariate association with the outcomes of p<0.2. Stepwise regression was used to determine a final model where the additional variables were only retained if they were significant at p<0.05. Trauma cases were excluded from the regression analyses to reduce the heterogeneity of the sample.
Beta β coefficient on log odds scale; p significance
[a] *n=218 – all medical PICU admissions; Not all included in all regressions due to missing data*
[b] *Not a 30 day outcome*
[c] *Variables the model was required to include*

Secondly, predictors of medical death by day 30 were assessed (Table 5-12). Children with more major impact modifiable factors (OR=1.25, 95%CI: 1.07-1.46) were more likely to have died by day 30.

Table 5-12 Outcomes of multivariable logistic regression on children with medical conditions

Children Dead by Day 30 (n=239)[a]	Odds Ratio	95% Confidence Interval		p
		Lower	**Upper**	
Outcome dead at 30 days				(*significant (p< 0.05)
Number of major impact modifiable factors	1.248	1.066	1.460	0.006*

Demographic variables, diagnosis, pathway variables, and global assessment of care were entered into the regression analyses if there was a univariate association with the outcomes of p<0.2. Stepwise regression was used to determine a final model where the variables were only retained if they were significant at p<0.05. Trauma cases were excluded from the regression analyses to reduce the heterogeneity of the sample.
p significance
[a] n=239 all medical cases (deaths and PICU admissions)

5.4 System Issues

Reviewers assessed whether there were “health system issue” prior to the acute episode which brought the child to the health care system that could have prevented or reduced the acute episode. A modified qualitative analysis of the free text comments by all reviewers identified the following main themes classified primarily by the level at which they occurred, see Table 5-13. In many cases the margins between health system deficiencies or omissions prior to the acute pathway and those which occurred within the acute pathway were difficult to separate. For example the lack of a well monitored high care ward at RCWMCH was identified as an issue (often meaning that children who might have been adequately cared for in a high care setting were admitted to PICU or where PICU admission was not possible deteriorated without high care monitoring and management. Is this a pre-existing health system issue? Or a failure in the acute pathway to care?

Table 5-13 Summary of health system themes identified in enrolled children

PRIMARY HEALTH CARE	
Access to Care	Across peak times, trauma peaks, for foreigners, for out of province patients
	Reduced access/ investigations/ staff over public holidays/ festive season
	Integration and communication between PHC providers
Cardiac	Examination (pulse oximetry) of neonates prior to discharge
	Consideration of cardiac aetiology for respiratory distress
City Health	City Health Clinic accessing EMS issues
	Triage/ eyeballing/ initial assessment
	Missing long term deterioration/ weight loss
GP	Communications with respect to referring patients
	EMS use by GPs
	Emergency management of critical child
	Missing weight loss/ severity
Neonatal	Inadequate examination prior to discharge – NB anus, cardiac
	Access MOU/ integration with CHC/ Clinic
General PHC	Missing deterioration especially loss of weight
	Accuracy first diagnosis critical
	Follow up of high risk neonates, children; HIV follow up
	PHC nursing training
CHC	Flow through CHC – lost in system
	Repeat visits to PHC for the same condition
	CHC staff discomfort managing small child
	Resuscitation skills
	Senior access/ review
Parent	Lack understanding/ explanation long term conditions/ issues
	Parental HIV education
	Parental knowledge of danger signs
	EMS access knowledge and use
	First Aid/ CPR at home
CLINICAL	
	Hospital systems to identify/ escalate for critical patients
	Red Flag child with vomiting only no diarrhoea
	Delay in antibiotics for septic shock
	Red Flag awareness and seeking TB meningitis
	Feedback of post-mortem results to PHC/ family
	RSI training/ high risk/ documentation of
	Documentation – especially date/ time/ name
	Triage – NB of respiratory rate, triage training and ancillary tests
TRANSFER and REFERRAL	
Monitoring prior to/ during	Inadequate while await EMS
PFS	Inadequate utilization/ Availability of PFS/ ALS
Dispatch	EMS call taker communication strategy
	Dispatch prioritization
General	EMS Management of neonatal sepsis
	Documentation
Critical Transfer	Paediatric (ICU) staff for long/ difficult transfers / Direct transfer system

	Safety of critical transfers
RCWMCH	
EC	Streamlining of investigations for critical cases
	Communication between specialties
	Surgical Emergency management process
	High Risk fast tracking
	Triage/ triage delays
	ENT access/ emergency review
	EC decision making/ senior review
	Short Stay Ward – admission criteria/ review/ protocols
	Septic neonate protocols/ management
Radiology	After-hours access and delays, ultrasound in EC especially after hours
	Monitoring and safety during imaging
ICU access	Delays, bed space, systems for dealing with “awaiting ICU bed” patient and monitoring during wait
OT	Delays to theatre, after hours assessment issues
	Pre-op assessment/ prioritization for OT
	Post-op/ peri-op planning (ICU bed booking)

ALS advanced life support; CHC community health centre; CPR cardiopulmonary resuscitation; EC emergency centre; EMS emergency medical services; Gastro gastro-enteritis ; GP general practitioner; HCP health care provider; HGT haemo-glucose test; HI head injury; HIV human immunodeficiency virus; ICU intensive care unit; ID identification; OT operating theatre; PFS paediatric flying squad; PHC primary health care

5.5 CAREGIVER PERCEPTION AND SATISFACTION

Caregivers, asked at the time of interview whether they were satisfied with the care delivered overall said they were satisfied with the care in 76% of consultations overall as shown in Table 5-14. Satisfaction with treatment, timing of being seen and the explanation provided (this refers to the clarity of any explanation of the child's condition and the management (if any) as judged by the caregiver) improved sequentially at higher levels of facility (with the exception of GPs who were perceived to be better than other primary care facilities), while satisfaction with communication (referring primarily to language comprehension between caregiver and health care provider) decreased from primary care to hospital based settings.

Caregivers were generally unhappy with the level of explanation given by EMS personnel, even though they were generally able to communicate (*i.e.* spoke their language) and they were mostly satisfied with the treatment rendered by EMS crew (Table 5-15).

Table 5-14 Reviewer assessment of quality of care and caregiver satisfaction with care and communication for each type of facility

FACILITY	Reviewer Assessment of Facility (n=641)*			Caregiver Reported Satisfaction with:#		
	Poor	Fair/ Good	Panel Dis-agreement**	Treatment (n= 561)	Explanation (n=559)	Communication (n=560)
Gender						
Medical	21.0%	68.6%	10.4%	75.5%	64.8%	72.4%
Trauma	8.6%	77.4%	14.0%	82.8%	80.4%	78.9%
Facility Level						
GP	59.1%	27.3%	13.6%	75.0%	71.4%	81.0%
City Health Clinic	35.1%	50.9%	14.0%	50.0%	46.3%	88.7%
CHC 24hr	39.8%	51.5%	8.7%	54.2%	44.2%	79.8%
District Hospital	20.0%	73.3%	6.7%	65.0%	65.0%	65.0%
Regional Hospital	4.0%	94.0%	2.0%	78.3%	82.2%	75.6%
Red Cross Hospital EC	10.8%	77.6%	11.6%	91.5%	73.8%	67.4%
Red Cross Hospital Ward/ OT	9.7%	75.7%	14.6%	85.5%	79.4%	66.7%
Other	10.0%	75.0%	15.0%	45.5%	28.9%	37.7%
Total Facility	19.2%	69.9%	10.9%	76.3%	66.4%	73.0%

GP/TH general practice; CHC 24 hour community health centre; RCWMCH Red Cross War Memorial Children's Hospital; other (private sector hospitals;, tertiary hospitals, midwife obstetric unit, community day centre)

**641 facilities were reviewed (including 29 operating theatre admissions)*

***Panel Disagreement – consensus was not sought for the assessment of each individual facility quality of care grading*

#Caregivers did not consistently respond to every question hence difference in denominators (e.g. caregiver interviewed were not always present for every steps of a pathway (such as the operating theatre)

Table 5-15 Reviewer assessment of quality of care and caregiver satisfaction with care and communication for each type of EMS transfer

EMS	Reviewer Assessment of EMS transfer (n=292)			Caregiver Reported Satisfaction with:#		
	Poor	Fair/ Good	Panel Dis-agreement	Treatment (n= 257)	Explanation (n=253)	Communication (n=255)
Type						
Medical	21.8%	70.7%	7.5%	73.8%	36.3%	74.1%
Trauma	5.7%	71.7%	22.6%	67.9%	55.6%	96.3%
EMS Level						
Home	6.1%	81.8%	12.1%	58.1%	40.0%	80.0%
Scene	3.0%	75.8%	21.2%	72.2%	47.1%	70.6%
Inter-facility	27.8%	63.9%	8.3%	72.9%	35.5%	80.1%
Paediatric Flying Squad	7.0%	90.7%	2.3%	82.9%	34.1%	61.0%
Flight	14.3%	57.1%	28.6%	83.3%	80.0%	81.8%
Highest Crew Qualification						
BLS	31.0%	59.5%	9.5%	61.5%	23.1%	87.2%
ILS	20.7%	70.7%	8.6%	78.4%	34.0%	82.0%
ALS	11.1%	81.3%	7.6%	77.7%	42.2%	69.2%
Dr	16.7%	66.7%	16.7%	66.7%	66.7%	66.7%
Triage Group[ǃ]						
Green	36.4%	54.5%	9.1%	45.5%	36.4%	72.7%
Yellow	33.3%	58.3%	8.3%	60.9%	40.9%	86.4%
Orange	18.6%	75.7%	5.7%	79.7%	32.3%	80.0%
Red	12.1%	79.0%	8.9%	75.9%	39.3%	70.1%
TOTAL EMS	18.8%	70.9%	10.3%	73.2%	38.3%	76.5%

EMS emergency medical services; PFS paediatric flying squad, BLS basic life support, ILS intermediate life support; ALS advanced life support; Dr doctor

**292 EMS transfers were assessed – some cases had none, but others more than one EMS transfer hence< 282*

***Panel Disagreement – consensus was not sought for the assessment of each individual facility/ EMS quality of care grading*

#Caregivers did not consistently respond to every question hence difference in denominators (e.g. caregiver interviewed were not always present for every steps of a pathway (such as the operating theatre)

**EMS call are prioritized by the dispatch centre – P1 is urgent and the target is a response time of 15 minutes, P2 is the next group with target of < 30 minutes.*

[ǃ] triage according to South African Triage Score: Red most urgent; green least urgent

5.6 DISCUSSION: OUTCOME ASSESSMENT

The assessment of the entire pathway was often a challenge in that a pathway can have multiple steps with variable quality of care at each stage – so the overall quality was a somewhat subjective (but consensus) agreement within the context of each case, with care graded as poor in 20% of cases. In the context of scarce PICU resources it is striking that 25% of PICU admissions for medical problems were assessed as being avoidable. Nearly 77% were assessed as being sicker than they needed to be at the time of admission. This was for many reasons including delay, inadequate management and possible therapies or decisions which may have prevented deterioration or improved the condition of a child. The implications of this are numerous but perhaps most importantly better care prior to PICU could reduce the pressure on PICU beds – by preventing admissions, and reducing the length of stay in PICU with better outcomes for others.

The original hypothesis of this research was to identify a group of children with good care and outcomes, and compare them to those with poor care/ outcomes, allowing identification of clear factors associated with both groups. Extensive analysis has not shown this to be the case. Firstly there were a minority of cases who had excellent care and outcome in all aspects (the more aspects you evaluate, the less likely it will be that they are all good), perhaps indicating an imperfect system. Secondly we could not identify any significance in the factors we looked at across quality of care and outcome variables – likely due to the heterogeneous nature of the cases and multiple different potential pathways (some appropriate and others less so), making it very difficult to identify children with good care and associate that with good outcomes. The results are nevertheless meaningful in allowing quantification of issues across the system and at different levels, and defining the problem issues as narrowly as possible for targeting improvement.

Trauma cases were different to medical in that avoidability of death and/or ICU admission was dependant on the injury rather than care (although in many cases high quality emergency care can reduce and secondary injuries with considerable impact on outcome) [258,259]. It would appear that the trauma cases that were admitted to PICU largely survived but had a prolonged hospital stay. Cardiac cases arrived in a worse state (higher predicted mortality on PICU admission) and stayed longer which is also as expected (correction of cardiac abnormalities usually required surgery and prolonged post-op recovery). But the single highest frequency group, the respiratory patients arrived with relatively low predicted mortality, stayed for some time (weaning from ventilator and extubating possibly) and did well, with reviewers largely satisfied with the quality of care and need for PICU, although many could have had some degree of avoidability of severity on arrival at PICU – often relating to antibiotic delay or omission (which was sometimes debatable in the face of apparently viral infection).

As discussed previously there were relatively few gastro-enteritis admissions, but those that were admitted had clear system issues and avoidable severity suggesting specific lapses in their care (perhaps easy to pinpoint with very specific protocols in place). All were discharged home after brief PICU stays – showing the transient nature of the illness and effectiveness of management. Children with sepsis were also judged to predominantly have avoidable severity of illness due to delays and omissions in time, fluids and early antibiotics as discussed in septic shock guidelines.[260]

An important question, given that there were more young children and infants admitted, was whether the care for these younger children was any worse than others (the hypothesis being that generalist doctors are less comfortable and competent in dealing with smaller babies)? The data are not particularly clear on this, there were certainly more system issues for neonates and infants largely relating to high risk babies, follow up, feeding and weight gain issues, all suggesting education prior to discharge from maternity services might be of value, as well as training and emphasizing these issues for PHC practitioners. Neonatal services in the province are also under increasing pressure with an increase in facility births in the last decade, without significant increase in facilities or resources.[43] There was more avoidable severity for the younger age groups which supports this hypothesis, and older children (many of them being trauma cases) received better care with more unavoidable PICU admission and severity.

Multivariable regression, although a powerful tool in eliminating confounding issues, has not produced particularly noteworthy results from these data, perhaps reflecting that the data may not be powered for this analysis. The regression relates only to the objective outcomes, and these are not clear markers of the quality of care in the pathway prior to PICU. Reviewers were aware of the outcome in most cases, so this may have influenced the allocation of modifiable factors. Other findings are harder to understand or explain, for example why respiratory diagnosis is linked to a lower predicted mortality, and increasing delay from onset of illness to presentation with lower predicted mortality, perhaps explained by different onsets of disease and the physiological basis of the PIM2 score (a very acute onset illness will likely be associated with a high PIM2 score, while a slower insidious onset illness may have less physiological reaction and a lower PIM2 score although the child is severely ill). Children who are underweight or malnourished, as well as cardiac cases are likely to stay in hospital longer while they gain weight, and recover from their surgery respectively.

The presence of system issues allowed reviewers to identify health care issues prior to the acute episode, and these were predominantly missed opportunities to intervene and prevent the development or progression to serious illness. Many of these themes are well established for public health and community paediatrics and are not novel, but it is useful that they have been identified and are largely amenable to improvements.

The consensus process was not flawless, but in general there was good agreement between reviewers. A good deal of the consensus meeting discussions related to whether severity was avoidable or potentially avoidable – often a "grey" zone as to whether a particular intervention might have helped or not – such as antibiotics for viral infection, *etc.* The internal reviewers were well matched – no single individual grading significantly better or worse than others. The external reviewer for the reasons discussed was often not in agreement, but was not privy to discussions, and assessed fewer cases intermittently compared to the internal reviewers. The reviewers were consistent over the data capture period, without evidence of a change in grading standards – likely due to the consensus process, and the multistep, blinded assessment process encouraging objectivity for each case. Despite the outcome knowledge of the reviewers in nearly all cases, there was no significant difference or association between the reviewer assessments of care and the objective outcomes (although the outcome knowledge may have influenced the grading and allocation of modifiable factors as discussed in subsequent chapters).

Caregiver satisfaction was largely congruent with the reviewer assessment of care, with the exception of the GP consultations, where caregivers were highly satisfied with most aspects of the consultation, while reviewers (with the insight of the outcome) were often critical of the care delivered. As in other countries[122], patients perceive the service from a GP to be better (fee for service as opposed to free/ subsidized public health care, less waiting, perhaps better facility “hospitality”, and perhaps a more personal approach), but on the other hand GPs are often operating at the junction of the private and public health care sectors, limited by their patient’s resources, and apparently unaware or unwilling to use and activate the public health service systems such as EMS or to discuss cases with a public sector facility/ clinician.

Caregiver satisfaction improved with higher levels of facility, reflecting a widely held perception that care at bigger and more central/ specialized hospitals is better, a finding which the reviewers largely echoed. Conversely though, communication (*i.e.* same language spoken) deteriorated with higher level facilities – likely reflecting PHC health care practitioners practising in their own communities, while higher level and specialist care is delivered by other language group practitioners – perhaps a remnant of apartheid and educational disparities between language groups. EMS data highlight the need for practitioners to explain their actions to caregivers, and even when EMS staff are unclear what is wrong with a child, they should explain what they are doing and reassure caregivers and patients.

In conclusion, through a rigorous, blinded and somewhat laborious process, quality of care was assessed subjectively for a large number of consultations and transfers of critically ill and injured children. Although there are weaknesses in the assessment methods used, this presents the most meaningful assessment possible across the range of the referral pathway health system interactions. As further analysis demonstrates, objective measures of outcome are complex and there is no one measure which gives any indication of the quality of care prior to PICU admission. Relating the clinical assessments to the caregiver’s issues and perceptions highlights an important aspect that may be neglected in what should be a patient centred system. Although keeping the caregiver (and the patient) happy and satisfied is not always a priority for healthcare providers (who focus on clinical throughput; and morbidity and mortality), simple, low cost issues (such as translation services and greater efforts to talk to caregivers and explain their management decision) could give a great deal more caregiver satisfaction, improve the image of the health services (and particularly the PHC services) and perhaps influence patient access and flow through the system.

6 PATHWAY AND DELAY

6.1 INTRODUCTION

All critical illness is time sensitive, as shown by data looking at a variety of presentations such as trauma, septic shock, and cardiac disease where there is good evidence in both adults and children to show the clear link between delay in management and increasing mortality.[17,18,261-265] In some cases effective management can be performed at a low level of the health system, such as managing a child with dehydration from gastro-enteritis, while other patients will require higher level and sometimes intensive care management such as ventilation, inotropic support and specialized surgery.

Several researchers have explored the relationship between delay and mortality in the critically ill patient where the ultimate destination is the ICU. Most of the studies are limited to adults, but are likely relevant to paediatrics, perhaps with different thresholds for delay. Several large adult studies[266-268] from different settings around the world have demonstrated convincingly that delay in admission of EC patients to ICU increases mortality (by as much as 30% per hour of delay)[266] and length of stay in ICU. All used different definitions for delay ranging from delay being anything over zero (68% of patients were delayed by this definition (median 17.8 hours (IQR 7.6-31.2)) in a Brazilian study)[266], more than 4 hours (61% (in the US))[268], to more than 6 hours (2% of patients (US))[267]. A strategy shown to be effective in trauma patients with long delays to ICU[193] was prioritizing which patients went to ICU first, with no effect on mortality of those de-prioritized. Depending on individual hospital practice and policy, it is likely that these prioritization are decisions are made on clinical grounds in many cases already (as they are at RCWMCH[71]).

There are few studies looking at delay in critical care for children, but one from RCWMCH in the study period[194] looked at trauma patients, and showed that children (of all acuities not just those for ICU) spent a median 225 minutes (IQR 21-303) in the EC with most delays due to administrative issues, obtaining radiographs (x-ray and CT scans) and specialist referral. No other published studies quantify the health service or facility delays (*i.e.* phase three in the three delay model) and their impact on critically ill children in an African setting, perhaps because of the magnitude of the first two phases of delay and just how much more difficult it is to access care in these settings. Studies looking at the first two phases have shown delays in accessing care (for critically ill children who died) of more than two days in Uganda[269], and another[96] in Tanzania, identified key issues hampering care for children who died being payments required for services, inadequate referral, inefficient organization, and lack of communication.

6.2 PATHWAY DESCRIPTION

Pathway characteristics

Over the study period data were collected from 22 GPs, 32 Clinics, 6 CHCs, 20 Regional/District hospitals, 292 EMS transfers, six RCWMCH wards, RCWMCH operating theatre and the RCWMCH EC. The 282 children had 641 consultations across these facilities.

For each of the 282 children in the study, there are data detailing their acute pathway from first presentation to PICU admission. In some cases there are overall trends and common pathways which provide useful information on the routing and flow of patients, but children's pathways from home through healthcare facilities to the PICU were often highly complex as shown in a simplified schematic Figure 6-1, with the outcomes at each stage detailed below and on the right. Detailed information on each case is given in Appendix III.

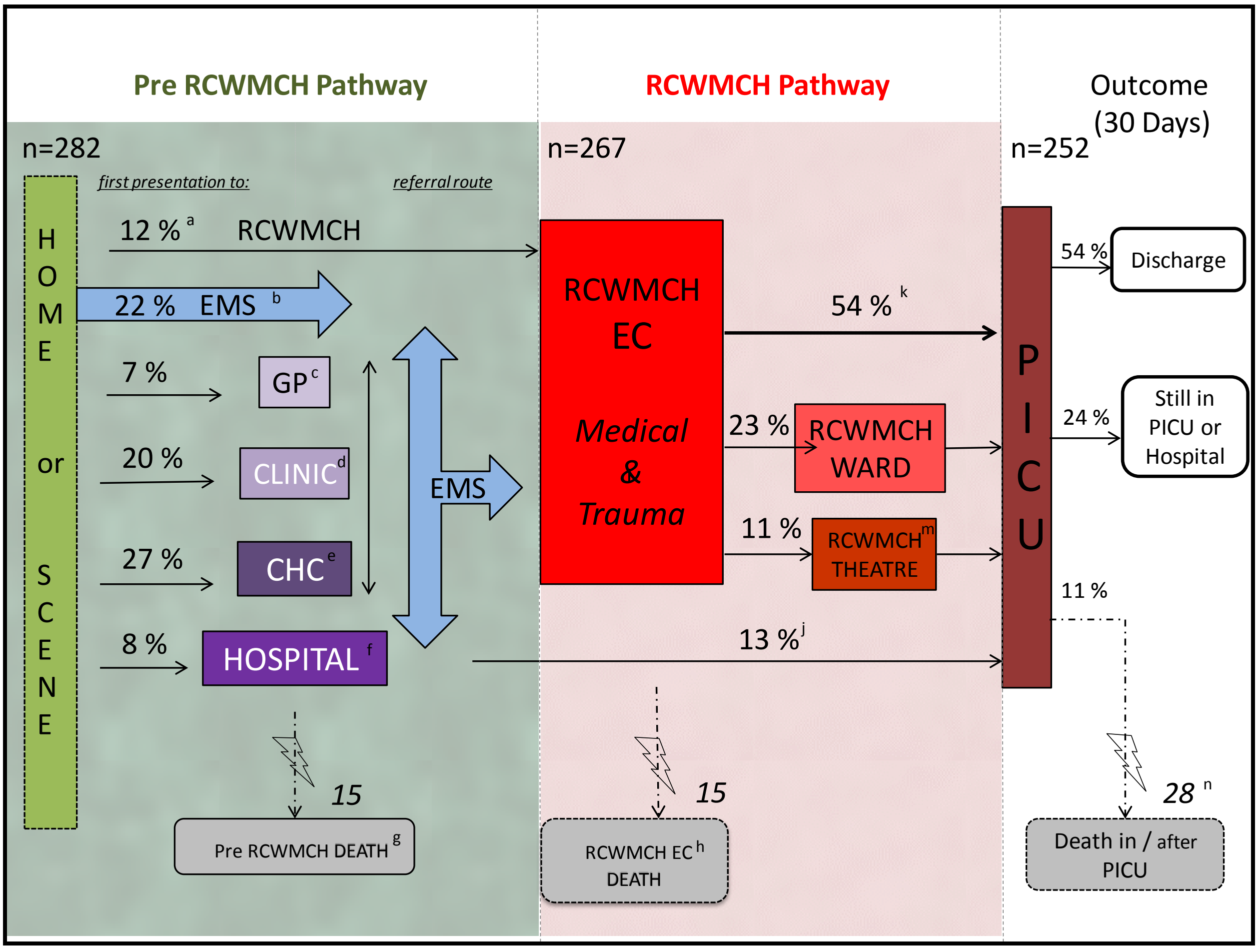


Figure 6-1 Simplified Overall Schematic of Pathways Patients

GP general practitioner, CHC community health centre, EC - emergency centre, PICU - paediatric intensive care unit, RCWMCH - Red Cross War Memorial Children's Hospital; EMS emergency medical services (ambulance)
**Only the site of first presentation and the RCWMCH flow is shown.*

(Detailed footnotes to Fig 6-1 are given below, but the following two figures Fig 6-3 and 6-4, which separate trauma and medical patients give more clarity and detail)

a Direct to RCWMCH without EMS 35 patients (12%)
b EMS – 63 (25 trauma, 38 medical) from home/ scene – 7 to CHC; 35 to Hospital; 21 patients (10 trauma, 11 medical) to RCWMCH
c GP – 20 (18 medical, 2 trauma) – 14 to RCWMCH (12 direct; 2 with EMS); others to Hospital (3), CHC (2), clinic (1)
d Clinic – 55 (all medical) – 12 to CHC (8 direct, 4 EMS); 17 to Hospital (4 direct, 13 EMS); 25 to RCWMCH (5 direct, 20 EMS) and 1 to GP
e CHC – 77 (10 trauma, 67 medical) – 58 to RCWMCH (1 direct, 57 EMS); 8 Hospital (1 direct, 7 EMS); 3 to a CHC and 8 Died at CHC
f Hospital – 22 (4 trauma, 18 medical) – 17 to RCWMCH with EMS; 2 to other Hospitals and 2 Died at Hospital
g Facility Deaths – 15 (13 medical, 2 trauma); 12 at CHC; 3 at Hospital
h RCWMCH EC Deaths – 15 (8 medical, 7 trauma) all via EMS from Hospital (5), CHC/ Clinic (4) or with EMS to RCWMCH (2) or direct to RCWMCH (4)
j Direct to PICU 32 cases – (1 trauma) – 13 from outside of Cape Town, 19 Cape Town – (15 from Regional Hospital, 3 other hospitals and 1 CHC)
m Theatre – 28 cases :14 medical (6 surgical, 4 neurology, 2 airway, 1 cardiac) and 14 trauma – (11 polytrauma/ head injury, 3 burns)
n Deaths Post PICU Admission: 23 in PICU, 5 after PICU discharge (palliative)

6.3 FACILITIES INVOLVED IN CRITICAL PATHWAY

The referral patterns of the PTC cases give some insight into the numbers and levels of individual facilities regularly involved in the care and referral of critically ill and injured children (Figure 6-2). Although there are many GPs and clinics in the drainage area, each individual practitioner or facility saw relatively few critically ill cases: most saw one or two, but all saw less than five PTC cases per facility during the study period. Those facilities which repeatedly managed critical children were the 24 hour CHCs (all had over 12 consultations), and some of the district and regional hospitals. By virtue of the sampling RCWMCH EC saw nearly all the public sector cases of paediatric critical illness (except deaths in sampled facilities and private hospital admissions).

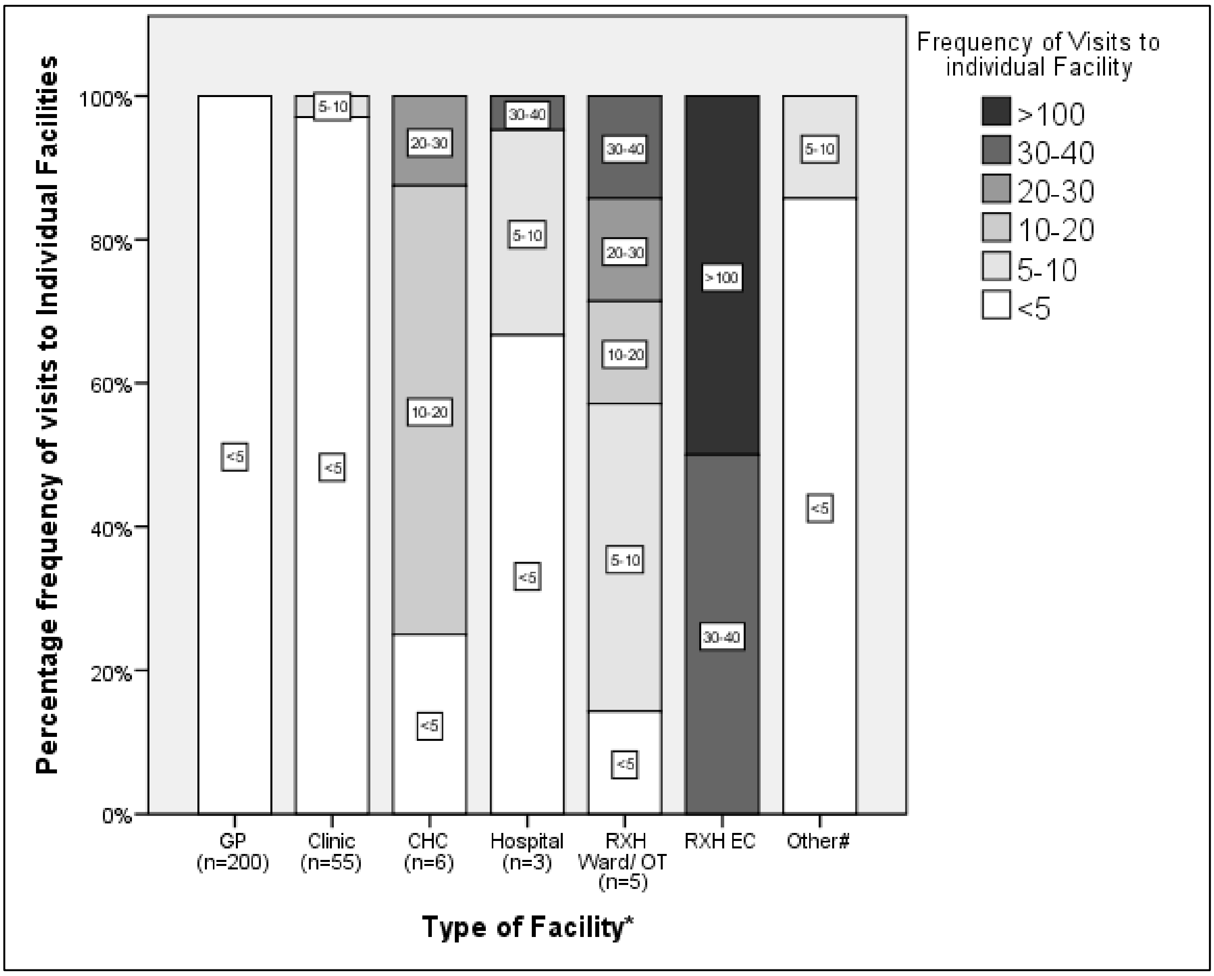


Figure 6-2 Frequency of Visits to Individual Facilities over study period (frequently visited facility types only shown)

** n is the approximate number of each type of facility within the RCWMCH referral area within the Cape Town metropol (of note RCWMCH EC is represented as 2 facilities – Medical and Trauma ECs*

 # other: private hospitals, tertiary hospitals, CHC daytime

6.4 PATHWAY ACCESS AND ROUTING SPECIFICS

First presentation for medical cases was a CHC in 68 (28.5%) cases, a clinic in 55 (23.0%), direct to RCWMCH in 33 (13.8%), EMS 38 (15.9%), or a GP 16 (6.7%) (Table 6-1). For trauma cases first presentation was predominantly to EMS in 24 (55%) cases and to a CHC 10 (23.3%). Prior to arrival at RCWMCH, 170 (60·3%) children were seen at just a single facility. A quarter (52, 25·2%) of caregivers of children with medical problems had consulted elsewhere prior to their first presentation at a healthcare facility and only a third (92, 33·8%) of caregivers knew the number to call for EMS. The vast majority presented after normal working hours (Monday to Friday 8h00-16h00) (142, 63.1% medical cases, 30, 76.9% trauma cases).

Table 6-1 Number, type and timing of health care facilities visited from initial presentation to PICU admission or death

	Medical (n=239)	Trauma (n=43)	Total (n=282)
First site in pathway			
General Practitioner	18(7·5%)	2(4·7%)	20(7·1%)
Clinic	55(23·0%)	0(0%)	55(19·5%)
CHC24	67(28·0%)	10(23·3%)	77(27·3%)
Regional/District hospital	18(7·5%)	4(9·3%)	22(7·8%)
Emergency Medical Services	38(15·9%)	25(58·1%)	63(22·3%)
RCWMCH	33(13·8%)	2(4·7%)	35(12·4%)
Other†	10(5·2%)	0(0%)	10(3·5%)
Number of facilities visited prior to RCWMCH			
0*	42(17·6%)	13(30·2%)	55(19·5%)
1	141(59·0%)	29(67·4%)	170(60·3%)
2	45(18·8%)	1(2·3%)	46(16·3%)
≥3	11(4·6%)	0(0·0%)	11(3·9%)
Number of facilities encountered at RCWMCH (including OT, excluding PICU)			
0**	44(18·4%)	3(7·0%)	47(16·7%)
1	124(51·9%)	24(55·8%)	148(52·5%)
2	52(21·8%)	12(27·9%)	64(22·7%)
3	19(7·9%)	4(9·3%)	23(8·2%)
Number of Operations (RCWMCH Theatre Cases)##	14(5·9%)	15(34·9%)	29(10·3%)
Number of EMS transfers			
0	60(25·1%)	5(11·6%)	65(23·0%)
1	128(53·6%)	24(55·8%)	152(53·9%)
≥2	51(21·3%)	14(32·5%)	65(23·.1%)
First Presentation [x]			
Office Hours	91(38·1%)	9(20·9%)	100(35·5%)
After Hours	148(61·9%)	34(79·1%)	182(64·5%)
First RCWMCH arrival[x] (n=267)[xx]			
Office Hours	81(35·8%)	8(19·5%)	89(33·3%)
After Hours	145(64·2%)	33(80·5%)	178(66·7%)
Consultation elsewhere prior to this pathway#	(n=206) 52(25·2%)	(n=22) 0(0%)	(n=228) 52(22·8%)
Knowledge of EMS phone number#	(n=231) 78(33·8%)	(n=41) 14(34·1%)	(n=272) 92(33·8%)

CHC24 24 hour community health centre; EMS emergency medical services; RCWMCH Red Cross War Memorial Children's Hospital; OT operating theatre; PICU paediatric intensive care unit

† Other includes Private Hospital (6), Midwife Obstetric Unit (4)

** indicates first access direct to RCWMCH*

*** indicates direct admissions to PICU (32) and deaths prior to RCWMCH (15)*

medical theatre cases included: CSF drainage (meningitis)(4); liver abscess, bronchial foreign body, ischaemic bowel (2), gastric ulcer, appendicitis, pericardial effusion, abdominal mass, anorectal malformation, intubation.

[x] office hours: Monday- Friday 8h00-16h00; after hours includes weekends and public holidays

[xx] 15 deaths prior to RCWMCH di not ever present to RCWMCH

 # Caregivers did not consistently respond to every question hence difference in denominators (caregivers interviewed were not always present for every step of a pathway (such as the operating theatre)

Caregivers were asked in the interview what they would do in the case of their child being very sick or badly injured, unrelated to the present events. Table 6-2 summarizes the responses. Another question probed parents on why they would not call an ambulance. Responses were mixed, 86 (30.5%) of respondents to the question said ambulances take too long, many saying they didn't know the number (15), ambulances do not come into their communities (6), that they had their own transport which was preferable (7), or it was close enough to walk to a health facility rather than call an ambulance (5).

Table 6-2 Summary of Caregivers planned response to emergency

Action Caregiver would take:	**For a very sick child** n=260		**For a badly injured child** n=259	
	n	%	n	%
Phone ambulance	91	35.0	146	56.4
Private car	63	24.2	51	19.7
Go to neighbour	58	22.3	37	14.3
Walk to facility	26	10.0	10	3.9
Take taxi	11	4.2	5	1.9
Hire a car	9	3.5	4	1.5
Go to police station	2	0.8	6	2.3

Detailed schematics for the PICU admissions are shown in Figure 6-3 **Error! Reference source not found.**(trauma cases) and Figure 6-4(medical cases) which illustrate the complexity of the pathways. Trauma cases showed much simpler pathways, with most first consulting at a hospital or calling EMS to the scene, and then seen at just a single (or no) facilities prior to RCWMCH. From RCWMCH EC, just over half the trauma patients went direct to PICU (with most others going via the operating theatre).
Medical cases in particular demonstrate the complexity of the pathway and referral process, although the main routes are home to CHC to RCWMCH or home to clinic to CHC. The majority of the emergency PICU admissions arrived at RCWMCH by ambulance from either a CHC or hospital and were transferred direct from the EC to the PICU.

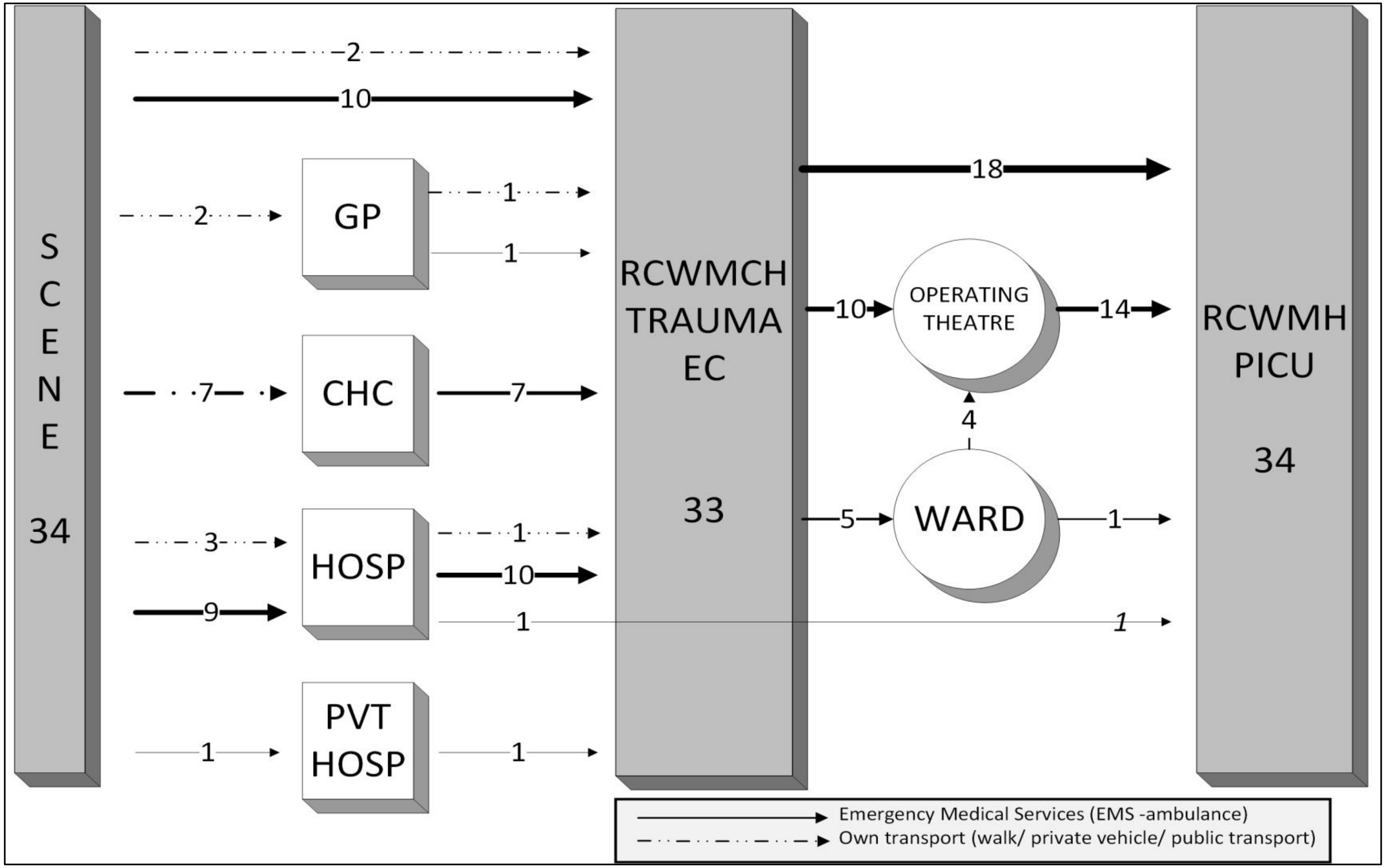


Figure 6-3 Schematic of the referral pathway for trauma patients admitted to Paediatric Intensive Care

GP general practitioner, CHC community health centre, HOSP - hospital (district and regional), Pvt HOSP - private sector hospital, MOU - midwife obstetric unit, ED - emergency centre, PICU - paediatric intensive care unit, RCWMCH - Red Cross War Memorial Children's Hospital; EMS emergency medical services (ambulance)

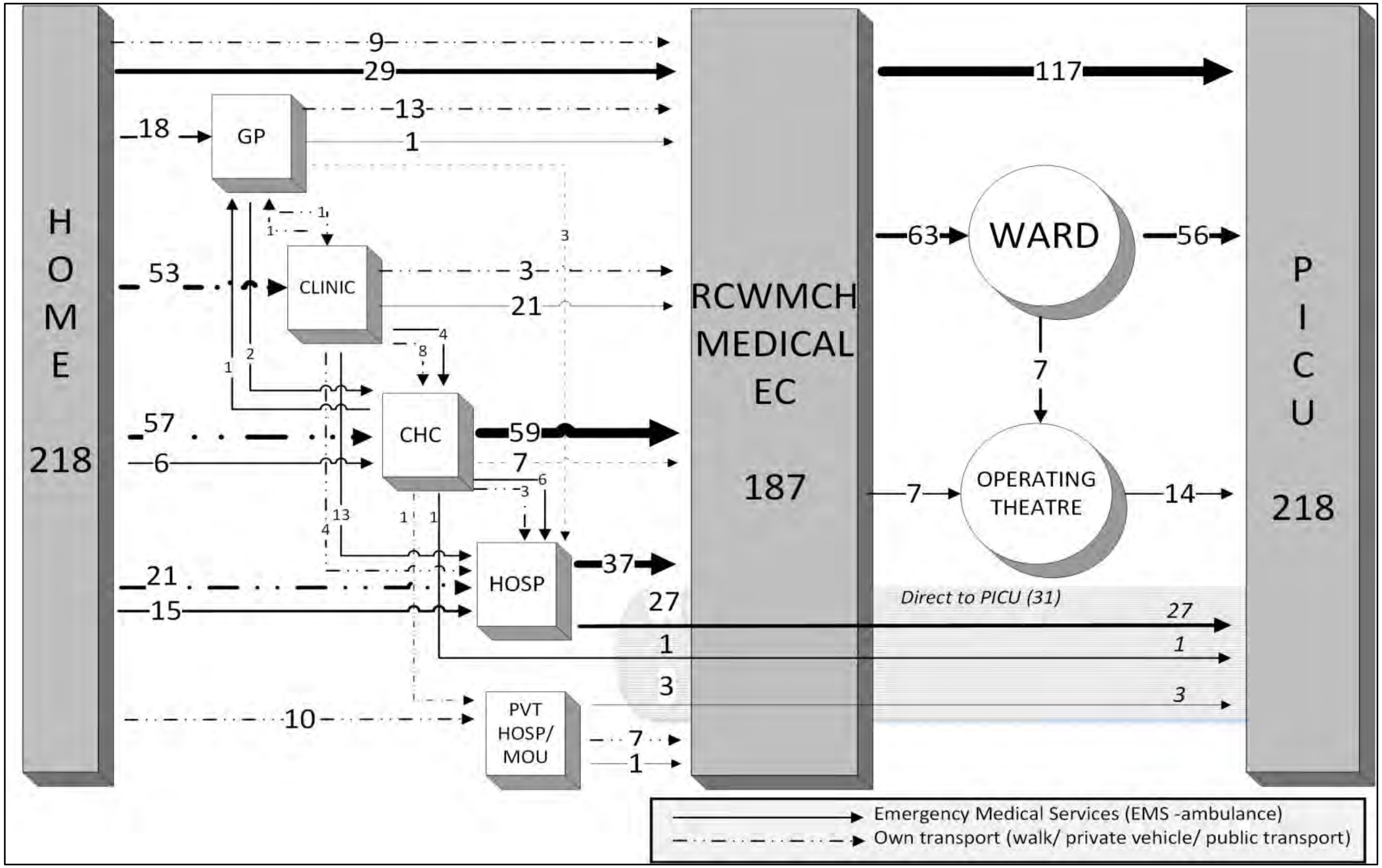


Figure 6-4 Schematic of the referral pathway for medical patients admitted to Paediatric Intensive Care

GP general practitioner, CHC community health centre, HOSP - hospital (district and regional), Pvt HOSP - private sector hospital, MOU - midwife obstetric unit, EC - emergency centre, PICU - paediatric intensive care unit, RCWMCH - Red Cross War Memorial Children's Hospital; EMS emergency medical services (ambulance)
This schematic is a simplification - there are complexities that cannot be represented here - there were discharges to home and return visits to facilities that are not shown, and there were 2 patients referred from RCWMCH to a lower level hospital who deteriorated and returned to be admitted to PICU.

6.4.1 Pre RCWMCH Pathways

Overall, 198 (almost 80%) of the PICU admissions either presented direct to RCWMCH or were seen at a single facility prior to RCWMCH:

- 49 (19.4%) children went **direct to RCWMCH** without any other facility consulted in the acute pathway – (30 without EMS, and 19 with an EMS transfer). Many of these patients had been seen at RCWMCH before, some were chronic patients with prior admissions/ surgery or a known illness being managed at RCWMCH.
- 149/252 (60%) children were **seen at a single facility prior to RCWMCH**:
    - 142 were transferred **by EMS** from a CHC (55/132 41.7%), a clinic (25/132 18.9%) or hospital (29/132 22.0%).
    - 17 cases arrived at RCWMCH **without EMS** – (12 from private sector GPs).

The remaining 54 patients were either seen and referred from one facility to another, or the patient re-presented to the same facility within 24 hours.
The median delay from first presentation to RCWMCH was 4.2 hours (IQR 1·7- 8·9). Delay lengthened with each additional facility visited (and non-linearly as second facilities were usually hospitals with overnight admissions so delay for those with 2 facilities was median 24.2 hours, 3 facilities 49.0 hours).
First presentation was in office hours in 85/252 cases (36.3%) only and first presentation at RCWMCH in office hours for 86 (34.1%) of cases.

Analysis of single facility referrals

Cases which were seen at just a single facility prior to arrival at RCWMCH represent a large proportion of PICU admissions and were thought to likely represent those with clear cut acute critical illness. Detailed analysis was performed on this group to see where the delays were prior to their RCWMCH arrival.
There were 136 cases (excluding deaths prior to PICU) who consulted at just a single facility in Cape Town prior to RCWMCH, comprising 123 medical (out of all medical PICU admissions (218) this group is 56.4% of medical cases and 13 / 34 (38.2%) of trauma. There were no clear differences in this group compared to the overall cohort in terms of PIM2 score, age, diagnosis, % arrived intubated at RCWMCH EC or PICU. The delay from first presentation to arrival at RCWMCH was median 3.8 hours (IQR 2.3-5.8). For **medical cases**, the facility consulted was a clinic in 24 cases, a CHC in 50 cases, and a hospital for 16; 16 without EMS transfer, 89 with a single EMS transfer, and 18 with 2 EMS transfers (*i.e.* an initial primary EMS transfer from home). Diagnosis was mixed, with the largest groups pneumonia (45/123 (36.6%)) and sepsis (23/123 (18.7%)). Of note for this medical single facility group only 86/123 (70.0%) were routed to PICU soon after arrival at RCWMCH, the remaining 37 went via a ward.

EMS

EMS were the primary responders to the home or scene in just 63 cases (22.0%), 25 trauma (so 24/43 (55.8%) of all trauma cases, and 38/239 (15.9%) of all medical cases. Reviewers assessed the appropriateness of using EMS, and 57 of these 63 cases using EMS primarily (90.5%) were judged appropriate.

6.4.2 RCWMCH pathway and delays.

Table 6-3 details the three routes of patients within RCWMCH to the PICU: those going direct to PICU from outside of RCWMCH, those admitted to PICU from the RCWMCH EC, and those admitted via a ward or operating theatre, and Table 6-4 shows pertinent outcomes for these groups.

In all, 32/ 252 (12.7%) patients were admitted **directly from another facility to the PICU** without going through the RCWMCH EC or wards. All but one of these patients were medical, and with two exceptions were referred from a district or regional hospital, in 13 (40.1%) cases they were referred from a distant hospital outside of the metropol. These cases all had clear indications for PICU admission, discussed and accepted directly by the PICU staff when there was a PICU bed available (or a bed was kept for the incoming patient) and in 26/32 (81.3%) PICU admission was not avoidable. The biggest groups were pneumonia patients (40.6%) who were either intubated or requiring imminent respiratory support, and cardiac cases (15.6%) for definitive management. In some cases patients at distant facilities may have been awaiting transfer to PICU for specialized management from another ICU and waiting for either transport or a bed to become available. These cases had the highest PIM2 score (median 8.6) and the longest PICU LOS indicating their severity and likely need for complex specialized management.

The largest group, 135/252 (53.6%) of PICU admissions were **seen only in the EC of RCWMCH and referred from there directly to PICU** (16 brought from home by parents but otherwise referred by another facility or EMS to RCWMCH). For this group, the delay from arrival at RCWMCH EC to PICU admission was a median 244.0 minutes (IQR 159.6- 349.8). On request of the EC doctor, 60% were accepted immediately for admission by PICU, and 92% within 60 minutes. Delay from acceptance to actual arrival in PICU was median 120.1 minutes (IQR 60.0 – 167.5), usually waiting for a PICU bed to be made available (usually involving selection and transfer out of a relatively "well" PICU patient). The primary diagnosis among this group of patients was similar to the overall cohort.

The remaining 85 (33.7%) of patients were admitted to **PICU from another ward at RCWMCH**. Time spent at RCWMCH prior to PICU admission varied, and time to acceptance for PICU median delay to PICU was 21.8 hours (IQR 10.6 – 48.7). Many of these patients were assessed and reassessed by PICU staff in the wards prior to their deterioration (or a PICU bed becoming available) and the decision to admit to PICU.
In terms of the time of presentation, all the above groups had a similar distribution of first presentation to the healthcare systems with around a third (36.5%) presenting in office hours; and likewise first presentation to RCWMCH 34.1% in office hours. Time of admission to PICU was only in office hours for 19.1% of cases, closer to the true time ratio of 23.8% of the hours of the week being "office hours" (8hrs x 5 days (40)) out of the total hours in a week (24hrs x 7 days (168).

Table 6-3 Detailed Description of Patients and Pathways according to routing within RCWMCH (for those admitted to PICU (excluding 30 deaths prior PICU))

Pathway once admitted to RCWMCH		Direct to PICU		EC to PICU		EC to Ward/ OT# to PICU		Total PICU Admissions	
		N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
		32	**12.6%**	**135**	**53.6%**	**85**	**33.7%**	**252**	**100**
Number of Facilities prior to RCWMCH	0	0	0.0%	28	20.7%	21	24.7%	49	19.4%
	1	14	43.8%	84	62.2%	51	60.0%	149	59.1%
	2	13	40.6%	19	14.1%	12	14.1%	44	17.5%
	>=3	5	15.6%	4	3.0%	1	1.2%	10	4.0%
Number of EMS transfers	No EMS	0	0.0%	28	20.7%	20	23.5%	48	19.0%
	1 EMS transfer	8	25.0%	81	60.0%	53	62.4%	142	56.3%
	>= 2 EMS transfers	24	75.0%	26	19.3%	12	14.1%	62	24.6%
Medical or Trauma	Medical	31	96.9%	117	86.7%	70	82.4%	218	86.5%
	Trauma	1	3.1%	18	13.3%	15	17.6%	34	13.5%
Diagnosis	Trauma	1	3.1%	18	13.3%	13	15.3%	32	12.7%
	Cardiac	5	15.6%	19	14.1%	3	3.5%	27	10.7%
	Gastro-enteritis	2	6.3%	7	5.2%	2	2.4%	11	4.4%
	Neurological	2	6.3%	11	8.1%	7	8.2%	20	7.9%
	Pulmonary Obstr	3	9.4%	10	7.4%	6	7.1%	19	7.5%
	Pulm Infective	13	40.6%	32	23.7%	33	38.8%	78	31.0%
	Sepsis	4	12.5%	23	17.0%	11	12.9%	38	15.1%
	Other	2	6.3%	15	11.1%	10	11.8%	27	10.7%
Time of First Presentation*	Office Hours	12	37.5%	51	37.8%	29	34.1%	92	36.5%
	After Hours	20	62.5%	84	62.2%	56	65.9%	160	63.5%
Time of First RCWMCH Presentation*	Office Hours	6	18.8%	56	41.5%	24	28.2%	86	34.1%
	After Hours	26	81.3%	79	58.5%	61	71.8%	166	65.9%
Time of PICU Admission *	Office Hours	6	18.8%	24	17.8%	18	21.1%	48	19.0%
	After Hours	26	81.3%	111	82.2%	67	78.8%	204	81.0%

RCWMCH Red cross war memorial children's hospital; PICU paediatric intensive care unit; OT operating theatre; IQR interquartile range
NOTE % refer to column%
**office hours: Mon- Friday 8h00-16h00; after hours includes weekends and public holidays*
 # OT (Operating Theatre) – 29 cases (medical (14); trauma (15).

Table 6-4 Detailed Description of outcomes for patients according to routing within RCWMCH (for those admitted to PICU (excluding 30 deaths prior PICU))

Pathway once admitted to RCWMCH		Direct to PICU		EC to PICU		EC to Ward/ OT# to PICU		Total PICU Admissions	
		N	%	N	%	N	%	N	%
		32	12.6%	135	53.6%	85	33.7%	252	100
Avoidability of ICU	Not Avoidable	26	81.3%	112	83.0%	53	62.4%	191	75.8%
	Potentially Avoidable	6	18.8%	21	15.6%	29	34.1%	56	22.2%
	Avoidable	0	0.0%	2	1.5%	3	3.5%	5	2.0%
Outcome at 30 days	Death in/ after PICU	5	15.6%	17	12.6%	6	7.1%	28	11.1%
	Still in Hospital	4	12.5%	33	24.4%	24	28.2%	61	24.2%
	Discharge Home	23	71.9%	85	63.0%	55	64.7%	163	64.7%
Risk of Mortality (%)	Median (IQR)	8.6 (6.2-15.6)		7.3 (2.1-21.0)		4.8 (1.7-12.6)		6.9 (2.0-16.6)	
PICU Length of Stay (hours)	Median (IQR)	105.8 (52.5-168.1)		77.0 (35.8-176.5)		74.7 (42.8-152.0)		76.9 (43.0-163.9)	
Time Interval RCWMCH-PICU (hours)	Median (IQR)	-		4.1 (2.7-5.8)		21.8 (10.7-48.0)		5.0 (2.5-12.9)	
Time Interval First-PICU (hours)	Median (IQR)	14.1 (5.5-50.1)		9 (6.1-14.2)		31.2 (16.1-60.2)		12.3 (6.9-39.6)	

RCWMCH Red cross war memorial children's hospital; PICU paediatric intensive care unit; OT operating theatre; IQR interquartile range
NOTE % refer to column%
**office hours: Mon- Friday 8h00-16h00; after hours includes weekends and public holidays*
 # OT (Operating Theatre) – 29 cases (medical (14); trauma (15).
Risk of Mortality- PIM2 Score

6.5 DELAYS

6.5.1 Introduction

Paediatric critical care has much overlap with adult critical care, but a key difference is the much more rapid deterioration of children and hence the importance of the timeline and reducing delays to care. This section (as well as elements of the prior section) will concentrate on developing an understanding of the delays in the pathway to care, as well as assessing their impact to reveal the common issues and bottlenecks in the pathways to care.

6.5.2 Overall Data

Overall, 75·0% of medical patients arrived at RCWMCH within 9·2 hours of presenting to the first facility, and 75·0% of trauma patients within 5·2 hours (Table 6-5). Median time from first presentation to PICU was longer for medical cases (median 13·8 hours, IQR (7·3-46·0) than for trauma cases (9·8, (6·3-16·0) although the ranges were wide (medical 1.6-233.3; trauma 3.8-115.7). EMS transfer durations were typically under 90 minutes. Time from arrival at RCWMCH to PICU admission was a median 5 hours (IQR 2·5–12·9).

Table 6-5 Time from illness onset to initial presentation, transfer and admission to Paediatric ICU

Length of pathway	**Medical (n=239)**	**Trauma (n=43)**	**Total (n=282)**
	Median (IQR)	Median (IQR)	Median (IQR)
Onset of illness to first presentation (days)	2 (0-4·0)	0 (0·0-0·0)	1 (0·0-3·0)
First presentation to RCWMCH presentation (hours)	4·4 (1·9-9·2)	1·9 (1·0-5·2)	4·2 (1·7- 8·9)
First presentation to PICU admission (hours)	13·8 (7·3-46·0)	9·8 (6·3-16·0)	12·3 (6·9-39·6)
RCWMCH arrival to PICU admission (hours)#	5·0 (2·4-15·9)	5·5 (3·1-8·1)	5·0 (2·5-12·9)
EMS activation to destination facility (minutes)*	(n=237)	(n=55)	(n=292)
	86·0 (56·0-124·0)	80·0 (48·0-128·0)	86·0 (54·0-124·0)

IQR inter quartile range; EMS emergency medical services; RCWMCH Red Cross War Memorial Children's Hospital; PICU paediatric intensive care unit
 # 32 patients went directly to PICU on arrival at RCWMCH (all had been previously accepted by PICU with a bed reserved for them); medical(31), trauma (1)
**** EMS was not utilized by all cases but some cases had more than one EMS transfer***

All but two children with trauma presented to RCWMCH on the day of injury, whilst 76·6% (183) of medical cases presented within 3 days of illness onset (it must be noted that the data for onset of illness varied substantially according to the source (caregiver interview *vs* various medical records) and these data are a combination representing the most likely onset from all data available). A subjective assessment by reviewers, made for each case overall was that there was clear delay in seeking healthcare in 133 (47.2%) of cases. This had no relationship to the outcome or assessment of quality of care for the cohort.
Table 6-6 shows more detail around the delay intervals for the various diagnostic groups. Gastro-enteritis and neuro patients took longer to present to the healthcare system, delays for trauma were less throughout, particularly prior to RCWMCH, but of surprise perhaps is the rapid transfer of the gastro-enteritis and pulmonary obstructive cases to RCWMCH.

Table 6-6 Delay Data for each Diagnostic Group

Diagnosis	Trauma	Cardiac	Gastro-enter-itis	Neuro-logical	Pulm Obstr	Pulm Infect	Sepsis	Other	TOTAL
Count Median(IQR)	*43*	*30*	*13*	*20*	*20*	*82*	*42*	*32*	***282***
Onset – First Presentation (days)	0 (0-0)	2 (0-6)	3 (2-10)	3 (1-7)	2 (1-5)	2 (1-3)	1 (0-3)	1 (0-3)	**1 (0-3)**
First Presentation - RCWMCH (hours)	1.9 (1.1-5.2)	4 (0-30.3)	2.1 (1.5-6.8)	5.7 (2.5-10.4)	1.6 (0-4.6)	4.7 (2.5-7.4)	4.6 (2.5-7.8)	4.4 (2.2-10.1)	**4.2 (1.7-8.9)**
Arrival RCWMCH – PICU (hours)	5.5 (3.1-8.1)	4.3 (1.4-6.3)	5.2 (2.3-10.9)	6.7 (4.4-13.9)	5.8 (2.7-44.1)	5.3 (2.1-26.2)	4.4 (2.3-9.1)	4 (2.5-10.9)	**5 (2.5-12.9)**
First- PICU (hours)	9.8 (6.3-16.0)	11.2 (6.1-51.1)	9.8 (7.3-26.8)	14.4 (9.5-19.6)	13.8 (4.7-60.0)	25.7 (9.2-57.0)	9.4 (6.2-18.1)	13.3 (6.8-27.3)	**12.3 (6.9-39.6)**

IQR inter quartile range; EMS emergency medical services; RCWMCH Red Cross War Memorial Children's Hospital; PICU paediatric intensive care unit

For those children admitted to PICU, 135 (53·6%) were admitted directly from the EC in a median of 4·1 hours (IQR 2·7-5·8). Other children were admitted to wards and had a longer and often overnight delay prior to PICU admission as detailed in Table 6-7. Since 25 (9.9%) of the PICU admissions were from outside the Cape Town metropol, time intervals for these children's presentation to RCWMCH have been separated from the local cases.

Table 6-7 Detailed Delays including only those who were admitted to PICU (excludes 30 deaths prior PICU)

Time Delays			Medical		Trauma		Overall	
			N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
Onset illness to first presentation (days)			218	2·0 (0·0-3·0)	34	0·0 (0·0-0·0)	252	1·0 (0·0-3·0)
First presentation to RCWMCH (hours)	Within Cape Town (n=227)		201	4·1 (1·8-7·4)	26	1·5 (0·8-2·3)	227	3·6 (1·5-6·8)
	Number of facilities visited prior to RCWMCH for Cape Town cases	0	37	0·0 (0·0-0·0)	12	0·8 (0·4-1·2)	49	0·0 (0·0-0·7)
		1	123	4·2 (2·5-5·9)	13	2·3 (1·8-3·2)	136	3·9 (2·3-5·8)
		2	35	10·2 (5·7-52·4)	1	19·3 (19·3-19·3)	36	11·3 (5·9-52·3)
		>=3	6	36·8 (18·1-95·0)	0	-	6	36·8 (18·1-95·0)
	Outside of Cape Town (n=25)		17	34·9 (13·3-73·6)	8	7·6 (4·5-10·1)	25	20·4 (6·3-49·0)
	Overall presentation - RCWMCH		218	4·4 (1·9-9·2)	34	1·9 (1·0-5·2)	252	4·2 (1·7-8·9)
EMS Intervals! (minutes)	Dispatch		237	7·0 (2-31)	55	3·0 (0-6)	292	5·0 (2-30)
	En Route1			13·0 (5-20)		10·0 (5-17)		12·0 (5-19)
	On Scene			24·0 (14-40)		35·0 (15-57)		25·0 (14-43)
	En Route2			19·0 (13-30)		19·5 (14-43)		19·0 (13-31)
	EMS Total			86·0 (56-124)		80·0 (48-128)		86·0 (54-124)
RCWMCH arrival to PICU (hours)	Direct PICU		31	-	1	-	32	-
	ED - PICU		117	4·1 (2·8-5·8)	18	3·3 (2·0-5·0)	135	4·1 (2·7-5·8)
	ED – Ward - PICU		44	23·4 (14·7-49·9)	1	113·8 (113·8-113·8)	45	24·5 (15·9-50·4)
	ED - Ward – Ward - PICU$^{\alpha}$		12	47·3 (28·3-77·8)	0	-	12	47·3 (28·3-77·8)
	ED – OT- PICU		7	7·3 (3·1-8·8)	10	6·9 (6·5-11·3)	17	7·2 (6·5-8·8)
	ED - Ward – OT -PICU $^{\alpha\alpha}$		7	30·0 (19·3-54·8)	4	27·5 (8·9-46·0)	11	30·0 (17·3-51·3)
	Overall RCWMCH to PICU		218	5·0 (2·4-15·9)	34	5·5 (3·1-8·1)	252	5·0 (2·5-12·9)
PICU bed request to PICU admission (hours)			218	2.5 (1.5-4.0)	34	3.0 (1.3-4.0)	252	2.5 (1.5-4.0)
First presentation to PICU (hours)	Within Cape Town		201	13·3 (7·1-41·6)	26	9·3 (6·3-16·0)	227	11·9 (6·8-34·8)
	Outside of Cape Town		17	40·5 (20·4-73·6)	8	10·3 (6·4-23·9)	25	30·0 (9·8-56·7)

IQR interquartile range; RCWMCH Red Cross War Memorial Children's Hospital; EMS emergency medical services; PICU paediatric intensive care unit; OT operating theatre

$^{\alpha}$ All but one case involved overnight admission from RCWMCH EC to an overnight/ short stay ward and then admission to a medical ward. A single case was referred as a "step-down" to a regional hospital and then deteriorated and returned to RCWMCH

$^{\alpha\alpha}$ 2 (medical) cases returned to a ward from OT and were subsequently admitted to PICU

! EMS delays are analysed per EMS trip and there were variable numbers of trips per case thus n=292

6.5.3 PICU Assessment and Review Time

As can be seen in Table 6-5 and Table 6-7, around half the time delay prior to PICU admission at RCWMCH was spent awaiting a PICU bed. When a clinician made a request for an ICU bed (usually telephonically to the PICU senior clinician), the PICU clinician would either accept the patient immediately, choose to assess the patient for PICU admission, or refuse outright. Once the PICU team had made the decision to accept a patient for PICU admission, there was another delay to get the patient to the door of PICU – either while a PICU bed was made available (often transfer of a stable PICU patient to a ward if no bed available), further investigations or consultations were necessary (for example neurosurgery assessment) or delay in the actual transfer. Table 6-8 details these intervals (where documented).

Table 6-8 PICU Assessment and Admission Delay for PICU Admissions

RCWMCH PATHWAY Time Interval *Median(IQR)*	**Direct PICU** (n=32)	**EC to PICU** (n=135)	**EC - Ward/ OT – PICU** (n=45)	**Total** (n=252)
Delay RCWMCH arrival to PICU (hrs)	0 (0-0)	4.1 (2.7-5.8)	21.8 (10.7-48.0)	5.0 (2.5-12.8)
PICU Request - Assessment (hrs)	0 (0-0)	0 (0-0.5)	0 (0-0.5)	0 (0-0.5)
PICU Acceptance – Admission (hrs)	2.8 (2-3.3)	2 (1-2.8)	2 (1.2-4)	2 (1.2-3)
PICU Request – Admit (hrs)	2.5 (2.0-3.0)	2.1 (1.4-3.5)	3.0 (1.4-4.5)	2.5 (1.5-4.0)

IQR interquartile range; RCWMCH Red Cross War Memorial Children's Hospital; EC emergency centre; PICU paediatric intensive care unit; OT operating theatre
(It must be noted that there was a good deal of missing data for these cases and some extrapolation as clinicians were inconsistent in documenting times of ICU request/ acceptance – in some cases it could be estimated from other events/ data, but in around 20% of cases could not be estimated (PICU request time missing for 53, PICU acceptance time missing for 23))

Table 6-9 compares the cases from within Cape Town and beyond in terms of this delay from PICU request to arrival. Most of the medical cases from outside of Cape Town went direct to RCWMCH. For trauma cases, the practice is that they are assessed by the surgical team in the EC prior to PICU admission (PICU staff are not surgeons), resulting in a longer delay in the transfer.

Table 6-9 PICU Admission Delays for Cape Town and non-Cape Town Cases

		Direct PICU		**EC to PICU**		**EC to Ward/ OT**		**Total**	
		Count	PICU Request to Admit (median hrs)	Count	PICU Request to Admit (median hrs)	Count	PICU Request to Admit (median hrs)	Count	PICU Request to Admit (median hrs)
Cape Town	Medical	19	2.5	114	2.25	68	3	201	2.5
	Trauma	0		13		13		26	
Outside of Cape Town	Medical	12	3.5	3	1.75	2	1.5	17	2
	Trauma	1		5		2		8	

EC emergency centre; PICU paediatric intensive care unit; OT operating theatre

6.5.4 Facility Level Based Delays

The data collection included times at various stages of the process within each facility shown in Table 6-10 – although it must be noted much of these data are dependent on who documented times and when (for example if a doctor documented the time on a child's notes this may have represented the time seen initially, or the time the notes were written (given that many of these cases were resuscitations demanding immediate intervention rather than initial note taking). Substantial delays are demonstrated at the clinic consultations, with a median 1.5 hours taken to be seen by the first health care practitioner. Total time spent at facilities without overnight admission capacity (*i.e.* GP, clinics and 24hr CHC) was clearly shorter.

Table 6-10 Delay intervals within different facility levels (for medical patients only)

Facility Level		Arrival to Nurse		Arrival to Doctor		Arrival to Depart	
	Count	Median (hours)	IQR	Median (hours)	IQR	Median (hours)	IQR
GP/TH	*22*			0.0	(0-0.5)	1.0	(0.5-1)
City Health Clinic	*49*	1.5	(0-2.9)			2.9	(1.5-5.3)
CHC 24hr	*104*	0.0	(0-0.3)	0.5	(0.3-1.3)	2.1	(1.3-4.1)
District Hospital	*44*	0.0	(0-0.1)	0.5	(0.3-0.8)	4.7	(2.7-6.3)
Regional Hospital	*50*	0.0	(0-0.2)	0.4	(0.1-1.0)	7.1	(4.1-24.3)
Red Cross Hospital Emergency Centre	*240*	0.0	(0-0.0)	0.6	(0.2-1.2)	3.8	(2.3-5.7)
Red Cross Hospital Ward	*75*	0.0	(0-0)	1.0	(0.5-1.7)	20.2	(12.6-41.0)
Other	*17*	0.2	(0-2.5)	1.0	(1-7.8)	4.4	(2.1-8.8)
Private Sector Hospital	*11*	0.0	(0-0)	0.0	(0-0.5)	3.7	(2.3-5.7)
RCWMCH Theatre	*29*	0.3	(0.2-0.4)	1.1	(0.7-1.3)	2.9	(2.0-4.2)
OVERALL	***641***	**0**	**(0.2-0.7)**	**0.7**	**(0.3-1.3)**	**4.1**	**(2.3-8.0)**
IQR interquartile range; RCWMCH Red Cross War Memorial Children's Hospital							

6.5.5 EMS Delays

EMS practitioners were better at documenting times and there were accurate and in-depth time data for each step of the EMS process. The process covered the time from a call from a facility/individual requesting EMS assistance, the information being routed to a dispatcher who allocated a vehicle and crew and dispatched them to the call, arrival at the scene or facility, departure from the scene/ facility, and finally arrival at destination facility as shown graphically in Figure 6-5.

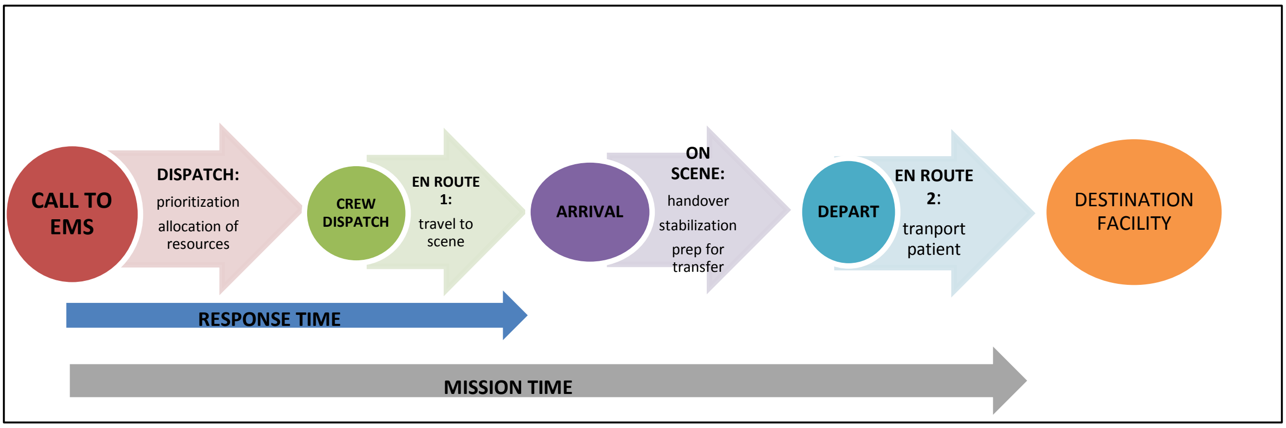


Figure 6-5 Graphical representation of EMS call out and transfer process and time intervals

Table 6-11 details each of these intervals, relative to the call type and crew. It is notable that EMS delay components are measured in minutes, with the total mission time seldom over two hours (except for long distance transfers). The majority (63.4%) of transfers were inter-facility transfers by non PFS vehicles, but with ALS crew present in many. Response time (*i.e.* call to arrival on scene) was a median 22 minutes (IQR 12-48), while time spent on the scene was substantially higher, especially for the secondary/ inter-facility transfers (which one would expect to be well prepared for transfer prior to EMS arrival but is likely not the case). Trauma calls were responded to faster, but had longer on-scene times.

The prioritization of children underwent a policy change almost midway through the study (1 March 2012) with a new policy that all children under one year of age are categorized Priority 1, regardless of source (*i.e.* home or health facility). Prior to this policy, 31/67 (46.3%) of the PTC EMS transfers were P1, after 125/172 (72.7%) were P1. This had a clear impact on the delays particularly for children awaiting EMS inter-facility transfers who had previously been de-prioritized relative to primary calls as shown in Table 6-12. The most improved delay is the dispatch time (although statistically non-significant (p=0.077), although all intervals appear to have improved.

The highest qualification of crew in an EMS vehicle was ALS in 144/ 250 (57.6%), although ALS practitioners represent only 11% of the EMS road crew personnel in Cape Town (personal communication S. De Vries, 2012).

Table 6-11 EMS Time Intervals for different types of call and crew composition.

EMS Call and Crew Composition		*Count*	Median Time Interval (minutes)				
			Dispatch	**En Route1**	**On Scene**	**En Route2**	**Mission Time**
EMS transfer type#	Home	*33*	4.5	15.5	16.0	16.0	**60.0**
	Scene	*32*	2.0	10.0	16.5	14.5	**50.5**
	Scene Flight	*2*	.0	15.0	8.0	12.0	**35.0**
	Inter-facility	*166*	8.0	9.0	24.0	20.0	**90.0**
	Paediatric Flying Squad	*46*	4.0	19.0	53.0	17.0	**107.0**
	Inter- facility Flight	*12*	3.0	86.0	97.0	121.0	**330.5**
Paediatric Flying Squad?	No	*216*	6.0	10.0	20.0	20.0	**74.0**
	Yes	*46*	4.0	19.0	53.0	17.0	**107.0**
EMS Call Type#	Primary	*67*	3.0	11.0	16.0	15.0	**56.5**
	Secondary	*224*	7.0	13.0	28.0	20.0	**95.0**
Aetiology	Medical	*237*	7.0	13.0	24.0	19.0	**86.0**
	Trauma	*55*	3.0	10.0	35.0	19.5	**80.0**
Priority of Call*	P1	*156*	4.0	13.0	26.5	18.0	**82.0**
	P2 (or >)	*83*	16.0	8.0	19.0	20.0	**96.0**
Highest Crew Qualification$	BLS	*42*	6.0	11.0	16.5	22.0	**60.0**
	ILS	*58*	5.0	7.5	15.0	16.0	**57.0**
	ALS	*144*	5.0	15.0	37.0	20.0	**98.0**
	Doctor	*6*	39.5	82.0	133.0	91.0	**245.5**
OVERALL	**ALL CASES median (IQR)**	***237***	**5 (2-30)**	**12 (5-19)**	**25 (14-43)**	**19 (13-31)**	**86 (53-124)**

 # EMS Transfer/ Call Types: Primary Calls are from the public to the home or scene of an accident (occasionally involving a flight (helicopter)); secondary calls are from one health facility to another – inter facility. Specialized secondary call types include Paediatric Flying Squad (PFS) which is a transfer by one of two dedicated vehicles and crews equipped specifically for critically ill neonates and children; and over long distances transfer would typically be in fixed wing aircraft with a high level transfer crew on board.

Priority of call – the EMS call taker and dispatcher allocate a priority code to each call – P1 (urgent) patients have a target of a response time (call to arrival) of 15 minutes, P2 – 1 hour. Most children < 1year are prioritized as P1.

$ EMS qualifications: BLS Basic Life Support – basic first aid skills only; ILS – Intermediate Life Support – limited ability to manage children; ALS Advanced Life Support – paramedic with advanced training including paediatric knowledge and skills.

Table 6-12 Effect of new EMS prioritization policy on time intervals

Time Interval	Prior 1 March 2012 n = 74	After 1 March 2012 n= 163
	Median (minutes) (IQR)	
Dispatch	12 (2-51)	4 (1-19)
En Route1	12 (4-17)	12 (6-20)
On Scene	27 (14-45)	24 (14-42)
En Route2	21 (14-46)	18 (12-28)
EMS Total	**32 (13-66)**	**20 (11-45)**

6.6 DISCUSSION

Pathway and Delay Discussion

6.6.1 General

The data provide much insight into the health seeking behaviour of parents, as well as the common referral routes that sick children take in the metropol. Despite a seemingly high number of health facilities in the metropol, many caregivers work (or seek employment) in office hours, and have limited access to transport after hours (there is little or no formal public transport after hours in most areas of Cape Town), so access to emergency health care after hours is difficult. Parents were hesitant to call for an ambulance for a sick child, and would rather wait until office hours to present to a nearby/ familiar facility (hence the higher number of presentations in office hours (33 - 35%), although office hours only represent 25% of the week). Parental delay in presenting to the health system was clearly an issue – and may point to the difficulty in accessing care. In many cases parents had already consulted a practitioner prior to the acute episode: a traditional healer in some cases (not all disclosed either to the clinicians or to the interviewers) or a pharmacy/ clinic/ CHC.

It is clear from the data that managing a critically ill or injured child is an uncommon or even rare event for most primary care facilities, yet at the 24 hour ECs at CHCs and in hospitals they were relatively common events. This is an important finding with respect to where the most effective implementation strategies for improving critical care may be. It is logistically much more feasible to improve care for these children at a small number of high frequency facilities than across a large network of PHC facilities and practitioners, although ideally services need to be improved across the system.

A major element of the contextual setting for each case and facility was the patient load and staff resources available at the time of the management of the critical child. The study did not collect any data on how busy (or not) the facility was, which may have added information if there was an easy way of collecting this information. International studies[270-273] have shown that overcrowding in the EC causes decreased quality of care for all patients, so this is clearly a factor which warrants further study.

6.6.2 Pathway

6.6.2.1 *General complexity*

The referral route or pathway that children were routed on was sometimes extremely complex. The longest pathway in the study involved four EMS transfers; three CHC consults, RCWMCH EC and then operating theatre (infant with TB meningitis who deteriorated over 48hrs). But the majority of cases had a relatively simple referral pathway from a single facility, by ambulance to RCWMCH EC and then to PICU. However even in a “simple pathway” there were four or more “handovers” to different teams and it can readily be seen that as the number of stages on a referral pathway increase the cumulative opportunity for delays and adverse events increases rapidly.

6.6.2.2 *Medical vs Trauma*

The results show a clear distinction in most respects between the medical and trauma patients. Trauma is a sudden (and in these cases catastrophic) event, and it is usually immediately obvious that the child is severely injured and will need specialist care – even to the lay public, but especially to health care workers. Perhaps because of the high incidence of trauma in the adult population (motor vehicle accidents and inter-personal violence) in the city, the health system and health care workers may be experienced with managing trauma in adults, but less so in children.[274,275] There are clear referral policies for trauma: major trauma triaged red goes direct to the tertiary hospitals, and health professionals may be more inclined to refer, or in the case of EMS, take patients direct to the tertiary hospital. So trauma has a briefer (median 1.9 hrs *vs* 4.4 for medical) and more direct pathway to RCWMCH, and better management in general. Once at RCWMCH, the delays for trauma patients are significant and similar, if not longer than those experienced by many medical patients. Some of this delay relates to more investigations (especially CT)[194] and in particular awaiting assessment by specialities, such as neurosurgery to assess and to make management decisions. Furthermore many trauma patients will require operations prior to PICU admission (10/34 29.4%).

Medical patients on the other hand may either present already critically ill (perhaps with late presentation), or may present with significant illness, but not yet severe enough to warrant urgent referral. It was sometimes difficult to distinguish retrospectively between a child who presents in the earlier phases of an illness and then deteriorates rapidly while in the health system (or after the first assessment), and the child where the critical illness is present but missed on initial assessment (especially the infant and neonate assessed by a generalist. Such cases are known to be difficult to pick up signs for those without a good deal of paediatric experience.[236] In some cases, especially in retrospect, there are clear gross abnormalities in vital signs and objective measures (oxygen saturation, blood gases) which indicate that the child was already significantly ill but were not interpreted correctly on initial presentation.

6.6.2.3 *Bypass/ Direct to PICU and Overcrowding*

An important issue raised is whether there is an adequate referral pathway for the clearly critically ill child at a peripheral facility to be referred rapidly and directly to an appropriate tertiary facility when necessary (*i.e.* bypassing and missing out steps). The trauma data show that it is possible in some cases. In theory RCWMCH EC will not turn away a critically ill child (objectively any child triaged RED), but there would seem to be a belief or a practice that every child needs to go through the same stepwise routing no matter how severe. Medical presentations may be more subtle, and lack of judgement (and/or not trusting the

judgement) puts the receiving institution and clinicians at risk if they accept apparently critically ill cases who turn out to be not as sick as described and overload their facilities.
The direct to PICU route from an outside facility was used primarily by paediatric specialists (both in Cape Town and outside) at regional hospitals who know the RCWMCH system (and PICU staff in some cases) and have the authority and are trusted by the PICU staff to select appropriate cases for PICU (those that will benefit from some aspect of the PICU care that they cannot receive elsewhere and are deserving in the prioritization of the scarce resources). These cases have clear cut reasons for PICU admission as in three quarters of such cases the PICU admission was not avoidable. Making the direct to PICU pathway more viable and open to non-specialist referral, in order to reduce the time and number of steps in a referral is perhaps a consideration, but will rely on accurate information from the referring clinician (who may over emphasize the child's severity in order to have the child accepted), adequate resources in the PICU to take and screen such requests, and PICU resources (beds) to accommodate such referrals at short notice (a reserve of "emergency" beds which are kept open to accommodate emergencies only without sacrificing efficiency of the PICU). A simple intervention which might streamline this process would be a dedicated paediatrician on call, able to give telephonic advice, and to advise and assist with expediting the referral process when necessary.

In many systems it is a function of the EC to receive patients from outside facilities and to make the judgement of whether ICU admission is necessary.[276] Often (especially where there is EC overcrowding) this function extends to stabilizing and monitoring the patient until such time as the ICU is able to admit the patient (the gatekeeping and holding function of the EC), but it requires resources in the EC to enable these functions without compromising new emergency patients.[9,163,277] There are no data from this study to define if and when the RCWMCH EC was overcrowded, defined as "an extreme volume of patients in EC treatment areas, forcing the EC to operate beyond its capacity"[278], but the numbers of critical patients seen were impressive given the physical capacity of the areas and the staffing. For example in in 2012 there were 37 900 patients seen in the medical EC (of which 40% were SATS red or orange), over 100 a day (but likely concentrated in peak periods), managed by between one and four doctors and two to three nursing sisters, in a four bed resuscitation bay and three consulting rooms (personal communication H. Buys, 2012).

6.6.2.4 *EMS Primary*

As reported elsewhere,[124,125] in this study it was found that an ambulance was called to the home of a sick child in only a small proportion of medical patients. It is unclear what the factors around this decision were. Many caregivers were unaware of the EMS phone numbers, and when asked why they would not use EMS for a sick or injured child, they largely blamed the EMS service for being slow, or unable to find addresses. It is unclear from the data why some parents called EMS for medical patients and others didn't and this is worthy of further qualitative studies. It must be noted again that although these data suggest that for those caregivers who did call an ambulance primarily it was largely appropriate, this study has no data on EMS call outs for children without critical illness to judge whether there was large scale inappropriate overuse or abuse of the EMS system by children who did not need an ambulance. Responses as to what parents would do for a childhood health emergency demonstrate again that for trauma, many more would call an ambulance, while for medical issues caregivers are more inclined to use other means of accessing healthcare.

6.6.2.5 *Hours of Presentation*

Given that conventional office hours in this system (8h00-16h00 weekdays) are only 40 of the 168 hours in a week (23.8%), this proportion was well reflected in the trauma patients (19-23 % presented in office hours), but medical presentations are weighted towards office hours (35-37%). This is likely because many caregivers choose to wait until office hours – perhaps because these are when the closer facilities to their home are open, the difficulty and danger of accessing facilities after hours, caregiver's awareness that there are more staff and better waiting times in office hours, and/ or an attitude that medical illness can "wait until morning". PICU admissions were fairly evenly spread between office hours and after hours for both trauma and medical cases. These data contradict other local evidence. For example the data from Cape Town CHCs[55] shows that CHC EC attendance peaks in the early evening 16h00 – 20h00 for paediatric patients, while regional hospital data[128] shows an office hour peak, but higher acuity patients present more after hours. Perhaps hospital referrals to the specialist hospital are likely to wait until morning for a senior clinician's decision, and the other facility data is skewed by the clinics which are only open in office hours.

6.6.2.6 *RCWMCH pathways*

Separating the PICU admissions into the three groups showed a sensible delineation of: 1) those admitted direct from outside RCWMCH – largely from another specialist and with clear cut priority and justification for specialist management from a PICU bed. Many were from regional hospitals in the metropol with limited intensive care capacity, and the remainder from outside the city for specialist care, including cardiac surgery, burns, trauma or other medical care beyond local capacity; 2) those admitted directly from the RCWMCH EC and these represent a group of identified critically ill patients needing urgent intensive care; and 3) those who either needed theatre, or were not sufficiently ill initially to warrant PICU admission but deteriorated during their initial hospital stay (although most were in PICU in under 24 hours). The first two groups were judged to be largely unavoidable PICU admissions, with a high risk of death and mortality rates so these were the sickest children. In the third group, more than a third could possibly have been kept out of PICU with better management.

6.6.3 Delay

Data around the timing of the pathway to care were collected at various points along the pathway, from different sources and with varying quality. The strength of having the caregiver's version of the timeline to compare to the medical records was that the two could be compared. Timelines from caregivers were often distorted (for most they were likely too worried about their ill child to watch the time and the perception of time was inaccurate, and perhaps prolonged when they were waiting for something, and fast when there were rapid events such as resuscitation *etc.).* For some caregivers, depending on their background and education, time is perhaps not such a central structure to their lives and is measured relative to events rather than absolute. Assumptions were made with which source to follow in some cases, and through data cleaning extraneous results were corrected/ removed where illogical/ impossible.

With so many data points, especially when there were usually several facilities visited, and occasionally multiple EMS transfers, assessment of the delays is complex and some summation was required. It was clear that the time intervals for trauma cases were different from those for medical cases (certainly prior to RCWMCH admission where there seem to be similar intervals) and this was a theme throughout. Although there were a relatively small number of trauma cases (43, 15%) they did seem to represent a unique group with a different pathway.

6.6.3.1 *Onset/ barriers to care*

This study undertook not to focus on the delays prior to presentation at health facilities and to thus avoid "blame" on the caregivers for possible late presentation. In fact all the reviewers were left with the distinct feeling that barriers to accessing quality healthcare were a greater issue than possible parental delay/ neglect, although this was only assessed by some limited probing to the caregivers around the timeline of the illness. Reviewers subjectively judged that there was an element of delay in seeking healthcare in almost half of cases though, whether this was because of real or perceived barriers to accessing the healthcare system, or inability to assess/ identify danger signs of a sick child for whatever reason would need further research.

6.6.3.2 *General*

The delays at each facility were striking given that these were largely very sick children. EMS were blamed in many cases by facilities and parents for delays, but had time intervals which were far shorter (measured in minutes as opposed to the hours of delay at other points in the process). Although numbers were not high enough to show clear relationships, it seems that children with trauma (already discussed), as well as gastro-enteritis and pulmonary obstructive disease (*i.e.* asthma, croup and upper airway obstruction) were routed through the system faster than other presentations (in half the time of overall first presentation to RCWMCH interval). In many cases these illnesses were clear cut and it was obvious when simple management would not be effective and rapid referral was required. Once admitted to RCWMCH there did not seem to be any difference in delays between diagnoses.

Analysis of the delays at each facility level was remarkable firstly for the delay from arrival to being seen by a nurse at clinics. These were nurse-run facilities, so a nursing assistant initially assessed the child (normally just weight/ temperature) while awaiting a registered nursing sister to see the child. These clinics saw mixed emergency cases and routine visits (vaccinations, growth assessments, *etc.*), usually with no differentiation or prioritization performed (it was strictly a "first come first served" basis and it was not infrequent that an acutely ill child waited in the queue for several hours to be seen and referred). The data for CHC visits was somewhat conflicting from the qualitative data which would have one believe that long waits were routine. Documentation of times was poor and the reality maybe worse than the data suggests. Overall times from arrival to departure are longer for the hospitals, where a paediatrician was often consulted and involved in the management/ assessment and decision to refer with consequent increased delay.

6.6.3.3 *RCWMCH Delay*

The largest delays were at the RCWMCH while awaiting a PICU bed, with largely undocumented monitoring and management in the interim (although care may have been better than was documented: ongoing monitoring with real time data and alarms if abnormalities develop are in place for some beds in the EC). Access to PICU beds was the single biggest delay factor in getting patients into PICU with delays averaging more than 2 hours. In all other settings the time taken to complete care processes do not seem unreasonable, particularly in the context of busy clinical services. However substantial reductions in delays could be achieved by measures such as elimination of unnecessary stages and use of parallel (rather than serial) steps in organisation.

Beyond the simple referral pathways (largely completed in under 24 hours), there were patients admitted to other hospitals prior to referral to the PICU. Sometimes these were the result of disease progression despite appropriate therapy (e.g. patients with adenoviral pneumonia deteriorating despite appropriate therapy). There were cases where in retrospect children should have been admitted directly to PICU, but beds were not available or disease severity was not assessed as being severe enough initially. Although only a small number of patients required emergency surgery at RCWMCH, there were substantial delays and obstacles to them being assessed by surgeons (particularly neurosurgeons) who offer an off-site service after hours, and in accessing theatre although in theory there are multiple theatres and teams on standby.

Although further sub-analysis of the delays for such a diverse group of children with unique pathways and contexts may not be appropriate, it can be seen from the data that for the apparently acutely ill group who were referred direct from RCWMCH EC to PICU, it took around median two hours to identify them and request a PICU bed. Given the clear acuity of many of these cases, it could be questioned whether this is reasonable, or an avenue for improvement through better identification, screening, triage or more senior staffing in the EC. Following PICU request, PICU assessment for the EC to PICU group caused little delay, but substantial delays of median 2 hours did occur in moving an identified and accepted PICU candidate into PICU. Patients who went to a ward may have deteriorated during their hospital stay, and may have been receiving high care in the wards so the decision to accept or reassess/ review later could reasonably have taken longer.

6.6.3.4 *EMS Delays*

There is a lot of detail in the EMS timing data because of good documentation. Probably most noteworthy is the effect of the change in dispatch prioritization protocols midway through the study on critical transfers which reduced the EMS dispatch time dramatically, but surely at the expense of other patients, *e.g.* high acuity adults, and lower acuity children and adults who would have had to wait longer for their transfers as a result. Prior to this change in policy, children at facilities were regarded as lower priority than other patients not at health facilities (*i.e.* primary calls) which may be true of many cases, but arguably not for the critically ill or injured patient at a facility unable to meet the demands of monitoring and managing their rapidly changing state.

EMS times spent on scene, particularly at a facility for an inter-facility transfer seem disproportionately long and probably reflect either children inadequately resuscitated and requiring stabilization and assessment prior to transfer, or facility staff who have been waiting for the EMS crew to assist them with stabilization/ intubation/ ventilation prior to transfer (especially in the case of the PFS called to transfer triaged red/ unstable children). These delays are surely amenable to reduction: an efficient collection of a patient at a facility should be achievable in well under 25 minutes within the metropol? Better qualified EMS personnel not only take longer to respond (they are in short supply and carefully prioritized/ rationed by dispatchers) but spend much longer on scene than the BLS/ ILS crews which reflects the limited capabilities and scope of practice of the BLS/ ILS whose main strategy with a critically ill or injured child is to “scoop and shoot” or rapidly transfer to an appropriate facility (this strategy is supported by some experts[279]) rather than spending time attempting stabilization on scene as ALS crews are likely to do.

Communication with the EMS was a significant problem with inappropriate allocation of ambulance crews to calls being all too common. It is unclear from the available data whether the miscommunications were from inadequate information relayed from facility staff calling EMS (in some cases nursing or clerical staff not directly involved in patient care), or from call takers and dispatchers at EMS with insufficient insight and understanding of the conditions and requirements to dispatch the appropriate crew and vehicle.

The PFS was a specialized service for high acuity children, used predominantly for neonatal transfers from maternity services, but also for paediatric transfers. Despite marketing and awareness campaigns, many PHC facilities and practitioners seemed unaware of the PFS (requested through a dedicated phone number) and would often call for EMS when PFS would have been more appropriate. EMS data (personal communication M. Lee, 2012) for the study period showed that the PFS vehicles and crews were under-utilized despite the number of transfer which could have benefitted from PFS.

6.7 CONCLUSION

There is no easy answer as to whether the delays experienced in this healthcare system are reasonable. On an individual level, most cases were from within the Cape Town metropol, close to a health facility. Transfer time within the city should not take more than 30-45 minutes. So is a median delay of 4.2 hours before reaching RCWMCH (including 86 minutes of EMS response and transfer time) reasonable? For a critically ill child, in all likelihood receiving little management further than a basic initial resuscitation (oxygen, some IV fluids, perhaps antibiotics) it is a long time. But from a health system viewpoint for a child to access the emergency area, get the appropriate administrative processes and a file opened in place, have the child identified as critical (through triage or more subjectively), wait to see a clinician, assessment by the clinician and resuscitative management as well as calling for EMS is this such a long time? Bearing in mind again that many of the facilities are overcrowded with long queues of mixed acuity, undifferentiated patients, and adults as well as children usually being seen by the same clinicians. There is little to compare to locally, as in the rest of Africa, PICU or specialist hospital referral and management is often just not available for the majority.[96,269,280]

In HIC there are variable data on the delay to adult ICU depending on the setting and with no way of comparing relative acuities. Adult studies show a range of EC to PICU intervals from 2.4 hours[281], 4.1 hours[282], and 4.9 hours[283]. There are no comparable studies on children. Management of particularly young children and infants is more time sensitive than adults, so the 4.2 hours from this study which is similar to some US adult studies is long by HIC standards for children. This study was unable to show that overall delay was directly linked to poor outcome, although other studies have clearly demonstrated this for EC – PICU delay. These data do however show that quality of care across the system was poor and there was a good deal of avoidable severity of illness in the pathway, much of which may be attributed to delays and complex pathway routings.

Medical patients requiring critical care are predominantly infants with a small number of frequent diagnoses (pneumonia, and sepsis), but for most children presenting with what appears to be an obvious critically illness, the pathway and referral is long and tortuous and there seems little reason why it can’t be straightened and shortened to the benefit of all.

CASE STUDY 2

ON was a 10 week old boy. He was born premature at 30 weeks gestation (1.075 kg) and had a complicated neonatal stay (hyaline membrane disease, sepsis, oxygen dependant for prolonged 5 week hospital stay). Weight now 2.2 kg. Live with his mother and two siblings in a high density informal settlement in Cape Town, single mother, Xhosa speaking with income R 500 – R 1 000 a month.

Mother reported a day of noticing ON was not breathing well. Late afternoon it seemed to be worsening so in consultation with a neighbour they decided to call an ambulance at 18h17. It took some time to come, but when it did it was a response car with an ALS crew initially (18h36), followed by ambulance.

EMS documented that the child was initially floppy, with oxygen saturation of 89% but improved on nasal prong oxygen. Unsuccessful IV attempt, elected to transfer without. EMS departed home at 19h12. Mother said she struggled to communicate with the ambulance crew and didn't really understand why there was a car and then an ambulance and where they were going but satisfied overall.

At the regional hospital (19h36), ON was rapidly seen in the EC and triaged SATS red, assessed as an "ex-prem with likely sepsis". He had several apnoeic episodes and began de-saturating. Investigations (CXR, blood gas) suggested sepsis with possible pneumonia. He was discussed and seen by paediatrics, and the decision was made to intubate and refer to RCWMCH for further management in PICU (discussed with RCWMCH PICU and accepted directly). Given ampicillin, gentamycin, ceftriaxone, and then intubated (20h20) successfully with ketamine and scoline. Mother said it was all explained well to her and she was happy with all aspects except the waiting for the ambulance to go to RCWMCH.

Transferred by the Paediatric Flying Squad, called at 22h10. EMS arrival at 22h55 and depart 23h50 with ON ventilated in an incubator, mother accompanying. Uneventful transfer with full monitoring.

RCWMCH PICU: Arrival 00h05 for 3 day stay with broncho-pneumonia. Microbiology all negative. Discharged to the ward and to home 8 days later.

<u>REVIEW</u>

Global Quality of Care: Good. EMS 1: Good; HOSP: Fair; EMS 2: Good.

Avoidability of PICU: Not Avoidable

Avoidability of Severity: Not Avoidable

7 DEATHS PRIOR TO PICU

There were 30 children enrolled who died before PICU admission and they have not been analysed extensively with the other data other than their demographics, as they were a somewhat different group, nearly all with shorter pathways, especially the 15 deaths outside of RCWMCH, yet there is much to be learnt from these cases.

7.1 LITERATURE REVIEW

There is a good deal of literature dealing with the death of a child in the hospital setting. For the parents and family, the death of a child is undoubtedly one of the most traumatic life events they will ever face, especially when sudden and unexpected.[284] Even for health care workers, the death of a child in your hands rates as one of the most difficult experiences to deal with[285], not only dealing with yourself and your staff, but particularly communicating the death to the parents/ family. There are unique aspects to dealing with the paediatric death beyond those relating to the death of an adult (which most health care practitioners are more experienced with).[286] A recent American Academy of Paediatrics policy statement[287-289] provides a standardized approach and management plan for a child dying in the EC, with great detail provided for the development and implementation of pre-existing protocols and policies which deal with the procedures to be followed, as well as outlining training requirements for health care workers.

In the last decade, much literature and research has emerged on family presence during resuscitation[290-297], which applies equally to the survivors of a resuscitation, but is likely more pertinent to the family members of those who do not survive. Many advocate that when the facilities and resources are there to provide for a family member to be present, it is likely a positive experience for the family member to see the efforts that were made to save their child. On the other hand, it may be uncomfortable for health care workers, particularly those who are not used to it, or not confident in their own skills to be observed, and this is likely the scenario in SA.[292] There is evidence that family presence during an unsuccessful adult resuscitation was a positive element with objectively less anxiety and depression after the event than those who had not been present, and did not interfere with the health care team or the resuscitation.[298]. Parents in the US were largely clear on their preferences to be present at their child's resuscitation, but the communication and management by the EC staff was vital.[290,299]

Surveyed emergency physicians[285] were unanimous in how difficult they found coping with and dealing with a paediatric death in the EC and how ill prepared they felt for the task, suggesting the need for training[300] (including simulation based training[301]) and services to assist and deal with staff traumatized by such a death.

There is limited SA literature on the child's sudden death and the emergency care thereof. Work in Kwazulu-Natal[302,303] has looked at deaths in the EC, although not all primarily from a paediatric point of view, including the development and implementation of systems to improve the management of a sudden death in the EC.[304] SA healthcare workers have been described by relatives of deceased as often cold and unsympathetic, delaying and evading through clerks and paperwork whilst loved ones were dying; providing lack of closure partially due to healthcare workers being evasive and not providing enough information.[303] Brysiewitcz[303], as well as Shelmerdine[305], writing about Cape Town EC doctors, put forward that health care workers become emotionally disconnected from their work (perhaps as a protective mechanism) and even with the shortages of adequate human resources need to be trained and have protocols guiding practice around dealing with a death. Brysiewitcz[306] comments on the lack of communication with families of deceased by health care workers on the procedures following a death such as the mortuary and post mortem as stressful and areas for improvement.

Grieving Xhosa mothers following early neonatal deaths in Cape Town[307] showed that lack of information and consequent unresolved issues around their child's death which led to prolonged and increased grieving. Searching for an understanding and reason for the death is a natural reaction, and for different individuals and contexts could be answered by religious beliefs, guilt and "why me" reactions, or looking at medical reasons and often associated concern over inadequate care (especially when there is a lack of communication). There is little data from the SA context giving insight to parents of recently bereaved children and their perceptions and desires around presence at the time of their child's death.

Although this chapter relates to deaths in health facilities, it should be borne in mind that many children die prior to seeking healthcare, or even following discharge from the health system, especially in LMIC settings, and there is likely a good deal of overlap between those who died prior to accessing health care and early in the health care system. [308,309]

7.2 Results

In the study period, 30 children were enrolled (10.6% of all enrolments) who died prior to PICU admission (15 at RCWMCH EC and 15 at other nearby health facilities) (Table 7-1). The reported delay from onset of illness to first presentation for the cases who died prior to PICU was less than a day for 20 (66.7%) of cases, suggesting a rapid (or instant for trauma) disease progression. More than three quarters presented after hours. All had a much briefer pathway with 28/30 (93.3%) visiting only a single facility, and 27/30 (90.0%) one or less EMS transfers. Death was considered avoidable or potentially avoidable in more than half of cases (17, 56·7%) and quality of care was considered poor in 40%.

These cases were significantly different (as compared to the PICU admissions) in the following ways: there were more trauma cases (p=0.017), global assessment of care was more often poor (p=0.04), there were more high impact modifiable factors (p=0.04) and delay from onset to first presentation was less (p=0.004). There were no other significant differences in the baseline characteristics, hours of presentation or clinical review outcomes between the two groups. Of note comparing the deaths at RCWMCH EC and other facilities, the only significant difference was less trauma deaths at other facilities (p=0.046), and in the diagnosis (more deaths of unknown cause outside RCWMCH (p=0.01).

As discussed in Chapter 10, many of these interviews were not easy for either the interviewer (several required counselling particularly related to interviews with caregivers of children who had died), nor for the caregivers, with 14/29 (48.3%) of caregivers admitting that they found the interview stressful when asked, as opposed to 24/246 (9.8%) of those whose children were admitted to PICU.

Table 7-1 Description of Deaths prior to PICU admission

		Deaths Prior to RCWMCH (n=15)		RCWMCH EC Deaths (n=15)		ALL Deaths prior PICU (n=30)	
Medical or Trauma	Medical	13	86.7%	8	53.3%	21	70.0%
	Trauma	2	13.3%	7	46.7%	9	30.0%
Diagnosis	Cardiac	0	0.0%	3	20.0%	3	10.0%
	Gastro-enteritis	2	13.3%	0	0.0%	2	6.7%
	Neurological	0	0.0%	0	0.0%	0	0.0%
	Pulmonary Obstr	1	6.7%	0	0.0%	1	3.3%
	Pulm Infective	1	6.7%	3	20.0%	4	13.3%
	Sepsis	2	13.3%	2	13.3%	4	13.3%
	Trauma	2	13.3%	7	46.7%	9	30.0%
	Unknown	7	46.7%	0	0.0%	7	23.3%
Global Quality of Care	Poor	7	46.7%	5	33.3%	12	40.0%
	Fair	6	40.0%	7	46.7%	13	43.3%
	Good	2	13.3%	3	20.0%	5	16.7%
Avoidability of Death	Not Avoidable	5	33.3%	8	53.3%	13	43.3%
	Potentially Avoidable	8	53.3%	6	40.0%	14	46.7%
	Avoidable	2	13.3%	1	6.7%	3	10.0%
System Issues	No	2	13.3%	7	46.7%	9	30.0%
	Possibly	6	40.0%	4	26.7%	10	33.3%
	Yes	7	46.7%	4	26.7%	11	36.7%
Number of Facilities prior to RCWMCH	0	0	0.0%	6	40.0%	6	20.0%
	1	12	80.0%	9	60.0%	21	70.0%
	>=2	3	20.0%	0	0.0%	2	10.0%
Number of Ambulances	No EMS	12	80.0%	5	33.3%	17	56.7%
	1 EMS transfer	3	20.0%	7	46.7%	10	33.3%
	>= 2 EMS transfers	0	0.0%	3	20.0%	3	10.0%
Delay onset illness to First Facility Presentation (days)	< 1 day	10	66.7%	10	66.7%	20	66.7%
	1 - 3 days	1	6.7%	2	13.3%	3	10.0%
	> 3 days	4	26.7%	3	20.0%	7	23.3%
Hours of first presentation	Office Hours	4	26.7%	3	20.0%	7	23.3%
	After Hours	11	73.3%	12	80.0%	23	76.7%

RCWMCH Red Cross War Memorial Children's Hospital; OT operating theatre; PICU paediatric intensive care unit; EMS emergency medical services

Other data of note relates to family presence during the final (unsuccessful) resuscitation. Caregivers were asked whether they were allowed to be present while their child was being resuscitated (at the time of death), and if they wanted to be there. Results showed that only 8/25 (32%) of parents who answered the question were allowed to stay with their child (35.7% at RCWMCH and 27.3% at other facilities); although 21/28 (75%) said they had wanted to be with their child. To relate this to the overall cohort, and all the facility consultations, 79.2% were allowed to stay with their children, and 88.5% wanted to be there with their children.

7.2.1 Details of deaths prior to RCWMCH

Deaths at the eight sampled facilities outside of RCWMCH included two trauma patients and 13 medical (of which 7/13 had an unknown cause of death. Although many had a post mortem, follow up of these results was difficult and deemed beyond the scope of the study so cause of death is postulated only for many of these children from the available information. Just 8/15 presented and died at a CHC, three presented and died at a hospital and the remaining four presented first to EMS or a CHC, had a single EMS transfer and then died at a second facility. Table 7-2 details each death, including secondary diagnosis, age and for those where the death was judged to be avoidable or potentially avoidable, the major issues reviewers identified are summarized. Only two cases were judged to be clearly avoidable deaths, one an infant seen with severe gastro-enteritis at a CHC, under assessed and given little resuscitation and died while awaiting transfer (without the priority it should have had). The other was an older child with a severe asthma attack, badly managed at the CHC, and then inappropriately referred even though deteriorating and unstable and arrived at a regional hospital in a dire state. In general the issues identified for these children were similar to the modifiable factors identified overall for the entire study with delays, inadequate/ under-assessment of severity and inadequate resuscitation being the frequent issues.

7.2.2 Details of deaths at RCWMCH prior to PICU

The 15 deaths at RCWMCH EC included seven trauma patients Table 7-3. Of these seven, five were assessed as being unavoidable deaths likely reflecting severe head injury incompatible with life, but requiring tertiary hospital (CT scan and neurosurgery) assessment to make this judgement. Of the medical patients, three had multiple and complex background pathologies and were judged to be unavoidable deaths. So 8/15 (53.3%) of these deaths were not avoidable, another six potentially avoidable, and one avoidable. The six potentially avoidable cases comprised two high risk cases with underlying pathologies, two with sepsis transferred from a CHC with apparently inadequate care from the CHC and delays, and two trauma patients referred from other hospitals with delays and poorly managed referrals. The avoidable death occurred in the RCWMCH EC overnight ward and was a direct result of inadequate assessment of severity followed by inadequate monitoring of a critical child inappropriately placed in a low care area by an unsupervised junior doctor.

Six out of 15 patients were first seen at RCWMCH (four presented directly (and all had chronic pathologies seen previously at RCWMCH), and two arrived from home/ scene via EMS), the remainder were referred from a CHC or hospital via EMS to RCWMCH where they died. Of note all the trauma patients were transferred by EMS. Details for each death are included below. The major issues overlap with those of the deaths prior to RCWMCH, but there would seem to be more issues relating to communication between healthcare workers, and monitoring of critical children.

Table 7-2 Details of 15 patients who died prior to RCWMCH admission (at CHC or Hospital)

Primary Diagnosis	Secondary Diagnosis	Gender	Age (mo nths)	PATHWAY			Global QOC[a] (P/F/G)	Avoid-ability of death[b]	System Issues[c]	Major issues
Gastroenteritis (A09)		M	10	CHC			P	Avoid	Y	CHC inadeq resus, poor referral; EMS delay and no management or monitoring in interim
Neonatal sepsis (P36.9)		F	0	CHC			F	P Av	Y	CHC neonatal resus substandard
Diarrhoea - gastroenteritis (A09)		F	16	Hosp			F	P Av	P	Hosp missed severity; inadeq monitoring and resus
Sepsis (A41.9)	trisomy 21, seizure	M	77	CHC	EMS	Hosp	P	P Av	N	Under-assessed at CHC & Hosp; EMS delays and miscommunication
Status asthmaticus (J46)		M	145	CHC	EMS	Hosp	P	Avoid	Y	CHC delays in decision making and referral, hospital management slow, poor resus, lack senior input
Pneumonia - inhalation of food or vomitus (J69.0)		F	4	CHC			P	P Av	P	CHC resus inadequate esp around intubation/ ventilation
Death - cause unknown (R96)	? SIDS	M	1	CHC			F	Not Av	P	
Death - cause unknown (R96)	Ex prem, ? post sedation sudden death	M	3	Hosp			F	P Av	Y	Unclear – perhaps under assessed. Death hours after elective hearing test
Death - cause unknown (R96)	Dandy-Walker malformation	F	3	Hosp			F	Not Av	Y	
Death - cause unknown (R96)	Ex prem ? septicaemia	M	5	CHC			P	P Av	Y	Access & triage delays at CHC; inadeq resus
Death - cause unknown (R96)	? SIDS ? suffocation	F	6	CHC			F	Not Av	P	
Death - cause unknown (R96)	? septicaemia	M	44	Clinic	CHC	CHC	P	P Av	Y	CHC under assessed; inadeq resus
Death - cause unknown (R96)	? septicaemia ? toxic shock syndrome	F	154	EMS	CHC		P	P Av	P	EMS & CHC under assessed; resus substandard; no consultation
MVA - pedestrian (V03.3)	Head injury (S09.9)	M	6	CHC			G	Not Av	N	
MVA - passenger (V49.9)	Head injury (S09.9)	M	4	CHC			G	Not Av	P	

CHC community health centre; Hosp hospital EMS emergency medical services; SIDS sudden infant death syndrome; MVA motor vehicle accident; resus resuscitation
a QOC quality of care (P poor; F fair; G good)
b Avoid avoidable; P Av potentially avoidable, Not Av not avoidable;
c Y yes; P potentially; N no

Table 7-3 Details of 15 patients who died at RCWMCH prior to PICU admission

Primary Diagnosis	Secondary Diagnosis	Gender	Age (months)	PATHWAY				Global QOC[a] (P/F/G)	Avoid-ability of death[b]	System Issues[c]	Major issues
Bronchopneumonia (J18.0)	trisomy 21, aspiration pneumonia	M	11	*RXH EC*				F	P Av	P	Poor communication between specialities; medical problems missed by surgeons; pre-existing illness
Bronchopneumonia (J18.0)		M	9	*Clinic*	*RXH EC*			P	Avoid *	Y	Inadequate assessment of severity and poor monitoring in emergency ward; missed deterioration
Bronchopneumonia (J18.0)	premature (29/40; 1kg) multiple pathologies	M	2	*RXH EC*				G	Not Av	P	
Cardiac arrest (I46.9)	congenital cardiac defect for elective correction	M	4	*RXH EC*				G	Not Av	N	
Cardiogenic shock (R57.0)	dilated cardiomyopathy secondary myocarditis	F	23	*EMS*	*RXH EC*			F	P Av	P	Communication between facilities, poor follow up
Congestive cardiac failure (I50.0)	congenital cardiac defect repaired, ? LRTI	M	10	*RXH EC*				P	Not Av	Y	
Septic shock (A41.9)	septicaemia	M	8	*CHC*	*EMS*	*RXH EC*		P	P Av	Y	Poor follow up, inadequate assessment on presentation, delays and RXH missed severity
Shock (R57.9)	sepsis/ toxin ingestion	M	4	*CHC*	*EMS*	*RXH EC*		P	P Av	P	Delays in CHC care esp antibiotics and transfer, lack of monitoring and inadeq resus
Gunshot injury (W34)	Head injury	M	107	*CHC*	*EMS*	*RXH EC*		F	Not Av	N	
MVA - pedestrian (V03.3)	Head injury	M	24	*Hosp*	*EMS*	*RXH EC*		F	Not Av	N	
MVA - pedestrian (V03.3)	Head injury	F	19	*EMS*	*Hosp*	*EMS*	RXH EC	F	P Av	N	Delay in transfer from peripheral hospital, followed by delays and poor care at RXH
MVA - pedestrian (V03.3)	Head injury	F	93	*Hosp*	*EMS*	*RXH EC*		F	Not Av	N	
MVA - pedestrian (V03.3)	Head injury	M	76	*EMS*	*Pvt Hosp*	*EMS*	RXH EC	F	Not Av	Y	
MVA - passenger (V49.9)	Head injury	M	65	*EMS*	*Hosp*	*EMS*	RXH EC	P	P Av	N	slow & uncoordinated management and transfer
Gunshot injury (W34)	Head injury	F	148	*EMS*	*RXH EC*	*Theatre*		G	Not Av	N	

RXH EC Red Cross War Memorial Children's Hospital Emergency Centre; CHC community health centre; Hosp hospital EMS emergency medical services; LRTI lower respiratory tract infection; MVA motor vehicle accident; resus resuscitation
a QOC quality of care (P poor; F fair; G good)
b Avoid avoidable; P Av potentially avoidable, Not Av not avoidable;
c Y yes; P potentially; N no

7.2.3 DEATHS in and AFTER PICU

Although not a focus of the study, which assessed the care up to the door of PICU, the 30 day outcome of all the PICU admissions was assessed and there were 28 deaths after PICU admission which are included for completeness.

7.2.3.1 *Deaths in the PICU*

These deaths are summarized in Table 7-4. Four cases would appear to be early arrest and death within hours of arrival moribund in ICU. The majority, 15/23 (65.2%), died within 72 hours of PICU admission, the remainder between 5 and 20 days with many of these being deterioration and multi-organ failure despite maximal treatment (largely with clear palliative withdrawal decisions prior to demise). ICU admission was judged inevitable for 16/23 (70.0%) of cases, but severity at admission was thought to be avoidable or potentially avoidable in 19/23 (82.6%) of these deaths. PIM2 score, the probability of death on PICU admission, showed a median 32% (IQR 7.5-61.5%). Of note were the two cases where death was thought to be avoidable: a neonate with septic shock judged to have an avoidable PICU admission and severity died from a strangulated hernia following 3 days of vomiting, missed at a clinic consultation on the day of admission; and the two month old with septic shock and avoidable severity died from overwhelming sepsis which had been missed at several prior consultations, with delay and resuscitation/ transfer issues prior to arrival at PICU.

7.2.3.2 *Deaths following PICU discharge*

There were five cases of which four (80%) were expected deaths with prior palliative decision who were transferred out of PICU to die. The fifth was a neonate with a volvulus/ imperforate anus where there was some delay and earlier management could perhaps have changed the outcome.

a. Tetralogy of Fallot – awaiting surgical decision and died unexpectedly in ward
b. Meningitis – advanced AIDS – palliative decision
c. Bronchiolitis/ Pneumonia and CNS malformation – palliative decision
d. Aortic anomaly – inoperable – palliative decision
e. Volvulus/ Imperforate Anus (palliation only - sent back to George Hospital and died there)

Table 7-4 Details of the children who died in PICU (in order of PICU length of stay)

Broad Diagnosis	Specific Diagnosis	Age (months)	PICU LOS (hours)	PIM 2 %	Global Quality of Care	Avoidability of PICU Admission	Avoidability of Severity	System Issues
Pulm Infective	Lower respiratory tract infection (J22)	3	0	99%	Poor	Potentially Avoidable	Potentially Avoidable	Yes
Cardiac	Cardiogenic shock (R57.0)	8	0	34%	Fair	Not Avoidable	Potentially Avoidable	Possibly
Sepsis	Septic shock (A41.9)	2	4	50%	Fair	Potentially Avoidable	Avoidable	Possibly
Trauma	Motor vehicle accident - passenger (V49.9)	4	5	64%	Fair	Not Avoidable	Not Avoidable	No
Other	Septic shock (A41.9)	0	13	32%	Poor	Avoidable	Avoidable	No
Neurological	Meningitis - tuberculous (A17.0)	25	15	94%	Poor	Potentially Avoidable	Potentially Avoidable	Yes
Other	Epidermolysis bullosa (Q81.9)	1	29	5%	Fair	Not Avoidable	Potentially Avoidable	Possibly
Neurological	Haemophilus influenza meningitis (G00.0)	13	33	5%	Fair	Not Avoidable	Potentially Avoidable	Yes
Pulm Infective	Pneumonia (J18.9)	7	37	0%	Fair	Not Avoidable	Potentially Avoidable	Yes
Neurological	Bacterial meningitis (G00.9)	1	43	2%	Poor	Potentially Avoidable	Potentially Avoidable	Yes
Other	Bowel necrosis (K63.8)	1	45	12%	Poor	Not Avoidable	Potentially Avoidable	Yes
Sepsis	Septic shock (A41.9)	1	52	83%	Poor	Not Avoidable	Potentially Avoidable	Yes
Sepsis	Septic shock (A41.9)	0	55	7%	Fair	Not Avoidable	Not Avoidable	Yes
Sepsis	Septic shock (A41.9)	0	61	92%	Fair	Not Avoidable	Potentially Avoidable	Yes
Sepsis	Septic shock (A41.9)	9	68	16%	Poor	Potentially Avoidable	Potentially Avoidable	Yes
Sepsis	Gram negative septicaemia (A41.5)	0	135	8%	Poor	Not Avoidable	Potentially Avoidable	Yes
Other	Liver failure (K72.9)	122	137	23%	Fair	Not Avoidable	Potentially Avoidable	Yes
Sepsis	Septic shock (A41.9)	2	159	29%	Fair	Not Avoidable	Potentially Avoidable	Possibly
Pulm Infective	Bronchopneumonia (J18.0)	3	164	2%	Poor	Not Avoidable	Potentially Avoidable	Possibly
Trauma	Head injury (S09.9) MVA	85	216	39%	Good	Not Avoidable	Not Avoidable	No
Pulm Infective	Pneumonia (J18.9)	4	444	72%	Fair	Not Avoidable	Not Avoidable	Yes
Cardiac	Myocarditis (I40.9)	56	478	59%	Fair	Not Avoidable	Potentially Avoidable	No
Cardiac	Dilated cardiomyopathy (I42.0)	30	490	40%	Fair	Potentially Avoidable	Potentially Avoidable	Yes

PICU paediatric intensive care unit; LOS length of stay; PIM2 paediatric index of mortality score

7.3 Discussion

The quantitative data for these children demonstrate their largely brief pathways to care, yet give little of the picture which the caregivers provided in the interviews. There were many emotive descriptions from parents, particularly from those with unexpected deaths at facilities where the parents' expectations of care were not met, as well as those where the parents had received little or no counselling or feedback from the system as to why their child died. In some of these cases there was an expectation expressed to the PTC interviewer that the study would provide answers, and in these cases it was brought to the attention of the relevant health facility managers to communicate with the parents. Further qualitative analysis of these particular interviews is underway. Our results suggest that policies for dealing with child death may well be overdue in this setting, where sadly the likelihood of dealing with a child's death is higher than in better resourced settings.

Caregivers' desires to be present at the death of their child were clear, three quarters wanted to be with their child during the resuscitation attempt, yet only around a third were allowed to be present. These data support international findings that parents want to be present and would find it beneficial.[290-297] Of concern, the frequency of caregivers not allowed in with their child points to the likely discomfort of medical staff (who would normally have the caregiver present while managing a child) who leave the parent outside while resuscitating a critical child, largely in cardiac arrest, with little chance of recovery.

The recruitment strategy to identify deaths at the seven identified facilities (five CHCs and three hospitals) in the immediate referring area of RCWMCH was not perfect, but the best that could be done without a system in place that identifies facility deaths rapidly. A larger study using death certification data would certainly identify more cases, but without the depth and insights that we were able to collect on these 30 cases. Identifying children who died at facilities was problematic in that none of the facilities kept separate records for children versus adults, nor did they separate deaths in the facilities from the many Dead on Arrival (DOA) cases who came to the facility primarily for death certification. We identified deaths through weekly communications with identified clerks at each facility in charge of the death administration process, and by checking the folders and registers (mixed adult/ child and DOA/ death) at each facility at regular intervals. It was startling in the recruitment process just how many DOA young children/ infants present to PHC facilities (CHCs), many with an apparently acute illness and little to see on inspection according to the notes. We elected to only include children who had some resuscitation and signs of life at the health facilities as we were assessing the quality of healthcare and the pathway to care rather than looking at causes of death in the community.

Almost half of the deaths were judged unavoidable so for these cases there is likely little that could have been improved other than better communication with the caregivers, and protocols and guidelines for dealing with a death. Health system issues which could have prevented the death were however present in two thirds of cases, suggesting there were missed opportunities to intervene in many of these children prior to the acute episode. For trauma patients there were clear road safety issues at play in every single case.

Many of the RCWMCH EC medical deaths were in patients who had previously been seen at the hospital, with pre-existing conditions under management from the RCWMCH specialist teams, judged by the parents or EMS to be the most appropriate place to take their child (even if this might have meant additional delay).

It is difficult to compare these results directly to other studies, because most other studies (as well as the ChIP data) largely look at in hospital deaths, which include a range of non-emergency deaths not included in this sample: neonatal deaths (prior to discharge home from maternity services), those dying in the wards after several days of care, and palliative deaths). The bigger picture is that from this small sample, the deaths were predominantly from pneumonia, sepsis and trauma which is not dissimilar to other hospital pictures in SA[310] or at RCWMCH[70]. The CEMACH reports have identified a high frequency of congenital abnormalities and prematurity related pathology in the UK deaths.[53] From these data there were eight out of the 21 (38.1%) medical deaths (prior to and at RCWMCH) attributable to either congenital or chromosomal abnormalities, and prematurity. As avoidable deaths decrease in this population with improving healthcare, these are likely to become the predominant causes of childhood death.

More details are available for RCWMCH deaths from the ChIP analysis for 2011 (unpublished data M. Hendricks 2013), although data are incomplete (there are no trauma data and even medical data collection was not 100%). These data look at 2011 and there were 180 audited deaths, hospital-wide, of which the top causes of death were septicaemia (21%), and pneumonia (12%), with most deaths in infants (50%). They identified from their audit the main modifiable factors being inadequate assessment, inadequate management of shock, use of antibiotics, response to danger signs, delayed referral and lack of monitoring, all congruent with the findings for the whole cohort in this study.

This small sample of deaths prior to PICU admission was included in the study because it was thought that looking at purely the PICU admissions would assess the group who had made it through the referral pathway and got to PICU alive, and miss the group who presumably had substantially worse care and died before they got to PICU, allowing identification of what went wrong in the latter group who died relative to those who survived to PICU. The data did not shown this to be the case – there was no clear distinction between the two groups or identifiable differences in what went right or wrong between the two. Many of the deaths were inevitable due to the gravity of the illness or injury or to underlying chronic illness, while the remainder seem to represent the same group as the main cohort who got to PICU, but just further in the continuum of illness or injury, and their care hampered by similar factors.

The ChIP database[219], and many of the international audits[200,209] focus on childhood deaths. While these are clearly an important target where things may have gone disastrously wrong, one of the key findings from this chapter is that the sample of deaths studied is different in many ways from the PICU admission cohort. The deaths included many unavoidable deaths (un-survivable trauma, congenital and chromosomal abnormalities and prematurity) and all had very short and abrupt pathways. Although the modifiable factors have a good deal of overlap with the PICU cohort, there was generally little pathway to assess and the medical management was a matter of a single terminal resuscitation in most cases, without many decisions or referral processes, or the chain of referral steps. So while there is indisputably a role for audit of children who die, these data show that auditing those who have critical illness and injury without dying may actually be more enlightening to a range of issues in the entire health system as this study has done.

8 MODIFIABLE FACTORS

8.1 BACKGROUND

As detailed in the literature review, one of the key components of the confidential enquiry is to identify specific avoidable causes where care was not optimal, and thus be able to recommend specific improvements for health services. Although there are various overlapping terminologies, modifiable factors were chosen, defined as factors or events which could be modified to improve care and reduce the risk of mortality and morbidity, by achievable interventions.[173] In order to assess specific issues encountered in the management of individual critically ill or injured children at each step and level of their pathway to care, it would be necessary to develop a list of potential modifiable issues. The literature is replete with classifications and taxonomies developed around adverse events, medical errors and suboptimal care.[199,233,311] Some classifications have been developed around the root causes of suboptimal care, such as McQuillan's[30]:

• Failure to appreciate clinical urgency.
• Failure to seek advice.
• Lack of knowledge.
• Failure of the organisation.
• Lack of supervision.

Others are more time and process based, looking at elements as the patient proceeds through the system[311], while a third approach is to classify by those responsible for the issue (and for improvements) which is usually along the lines of family/ community; health care providers; and administrators/ policy makers ("health system").[87] Table 8-1 demonstrates this approach with SA data for maternal and childhood mortality.

Table 8-1 Modifiable factors underlying SA deaths of mothers and children according to three national mortality audits (Bradshaw, D., et al., 2008)[87]

	Family and community	Administrators and policy makers	Health-care providers
Maternal death: *Saving Mothers (NCCEMD)*	44% of maternal deaths had a modifiable factor related to family/community action—eg, inadequate or no antenatal care	32% of maternal deaths had a modifiable factor related to administrator action—eg, absence of blood for transfusion, and no transport between health institutions	54% of maternal deaths had a modifiable factor related to health-care provider action at the primary facility level; 48% at secondary level; and 37% at tertiary level—eg, non-adherence to standard protocols
Stillbirths and newborn deaths: *Saving Babies (PPIP)*	38% of stillbirths and early neonatal deaths had a modifiable factor related to family/community action—eg, delay in seeking care during labour	19% of stillbirths and early neonatal deaths had a modifiable factor related to administrator action—eg, personnel not available or not sufficiently trained	35% of stillbirths and early neonatal deaths had a modifiable factor related to health-care provider action—eg, fetal distress not identified in labour, poor response to maternal hypertension
Infant and child deaths: *Saving Children (Child PIP)*	25% of all modifiable factors in child deaths were related to family/community action—eg, caregiver did not recognise severity of the illness	22% of all modifiable factors in child deaths were related to administrator action—eg, no senior doctors and nurses, and insufficient paediatric beds	53% of all modifiable factors in child deaths were related to health-care provider action—eg, IMCI not used in clinics, and poor assessment and management in hospitals

Child PIP=child healthcare problem identification programme. PPIP=perinatal problem identification programme. NCCEMD=National Committee on Confidential Enquiries into Maternal Deaths. IMCI=Integrated Management of Childhood Illness.

To facilitate this review, our requirements were a robust and simple list of common issues negatively affecting the care of critically ill children, across the health platform from first presentation, through to PICU admission or death, including multiple facility levels and EMS transfers. Existing modifiable factor lists were reviewed including:

1) Confidential Enquiry into Maternal and Child Health in the UK[53,197]

2) ChIP in SA[312] which uses a complex (10 page) list of modifiable factors[229] classified by who caused them (Clinical Personnel, Administrators, or Family/ Caregiver) and by site as summarized in Table 8-2. This list has been compiled and revised over several years.[313]

Table 8-2 Modifiable Factor Categorization from ChIP SA (Child Healthcare Problem Identification, 2013[229]

Where they occur / Who is responsible	Clinical Personnel	Administrators	Family/Caregiver
Ward	Clinical Methods Assessment Management Monitoring	Infrastructure Staff Consumables	Growth & development Disease prevention Home treatment Care seeking & compliance
Emergency & Admission	Clinical Methods Assessment Management Monitoring	Infrastructure Staff Consumables	Growth & development Disease prevention Home treatment Care seeking & compliance
Referring Facility & Transit	Pre-transit care in referring facility In-transit care	Pre-transit care in referring facility In-transit care	Growth & development Disease prevention Home treatment Care seeking & compliance
Clinic and Outpatient Care	Clinical Methods Assessment Management Monitoring	Infrastructure Staff Consumables	Growth & development Disease prevention Home treatment Care seeking & compliance
Home	Promotion Prevention Social support	Transport Community development	Growth & development Disease prevention Home treatment Care seeking & compliance

Although comprehensive, none of these lists was judged suitable for this research program as we were only looking at the healthcare facility issues, and specifically avoiding judgement and apportioning blame to caregivers, and we wanted a simple list that could be feasibly applied to a large number of cases and “steps” in their pathways. From these sources, we compiled a list of potential modifiable factors, and refined them by piloting on cases and consensus of the expert panel (Table 8-3).

These modifiable factors are subjective, and only allow quantification of the issue through the grading of impact. But they are universally applicable across healthcare levels, include EMS specific issues, and would be representative of the main issues we expected to find, and more importantly would feasibly be able to target for improvement in the local healthcare facilities and system. And in addition they would allow comparison to other analyses such as ChIP and CEMACH.

Modifiable factors for each step and case were allocated and graded by the Clinical Fellow (PH), and reviewed by the three expert panel members with comment, discussion and modification if they disagreed. Definitions were then developed for the possible impact of these factors:

- Major Impact – factor had clear negative impact on the outcome for the patient (worsened mortality or morbidity). It was directly and an overwhelmingly important factor in the severity of illness/death.
- Minor/Moderate Impact – factor which on its own had minimal negative impact on the outcome but may have caused some morbidity and/or extended the hospital/PICU stay.
- Near Miss – unplanned event that did not have major impact– but had the potential to do so. Only a fortunate break in the chain of events prevented an injury, fatality or damage.

- No Defined Impact – factor which has no individual or cumulative negative impact on the outcome of this or future case.
- Not known – cannot be established or estimated given facts known about scenario.

Table 8-3 Modifiable Factors Applied in each Facility or EMS Assessment

FACILITY	**COMMUNICATION**
Accessibility of Emergency Care area/ personnel	Explanation to caregiver
TRIAGE	Communication death issues
Inadequate assessment at triage	Other
Triage mechanism misses critical patient	**EMS**
Other	Communication with call centre at initiation of transfer
INITIAL ASSESSMENT	Communication from control to dispatched crew
Missing key findings (history/ clinical)	Prioritization of call out
Inadequate assessment/ interpretation of severity	Dispatch time delay
Investigations inadequate	Transfer time excessive
Investigations excessive	Response time delay
Missed/ incorrect diagnosis	Inappropriate vehicle/ crew/ equipment
Other	Inadequate stabilization for transfer
MANAGEMENT	Inadequate assessment before transfer
Delay in critical management decisions	Inadequate monitoring en route
Resuscitation not done/ inadequate for shock	EMS clinical management decision
Airway management	EMS disposal decision
Ventilatory management	Other
Circulatory management	**OPERATING THEATRE (those not covered above)**
Haemo-glucose test assessment and management	Anaesthetic Pre-op Assessment Inadequate
Antibiotic therapy	Anaesthetic Senior not called pre-op
Analgesia	Surgical Pre-op Assessment Inadequate
Temperature management	Surgical Senior not called pre-op
Electrolyte abnormality management	Delay pre-op
Trauma Immobilization	Anaesthetic technique
Delay in disposal decisions	Fluid Management
Other	Surgical technique
CONSULTATION	Delay on table
Inadequate supervision of junior staff	Delay in calling senior for assistance
No consultation to on site seniors	Recovery Process issues
No consultation to offsite specialists	Delay in transfer out
Senior review of patients (e.g. ward round) inadequate	Other
Delayed consultation	**DOCUMENTATION**
Other	Missing date/ times
REFERRAL	Missing / poorly documented information
Inappropriate referral destination	Other document issues
Communications with receiving facility	**RADIOLOGY**
Call/ information given to EMS about transfer	Delay awaiting radiology
Inappropriate referral mechanism (e.g. taxi/ private transport)	Delay in performing radiology
Inadequate stabilization for transfer	Delay reporting radiology
Ongoing monitoring/ management while awaiting transfer	Radiology findings missed/ misinterpreted
Referral Delay	Other
Other	**ADVICE TO PARENTS**
	No documentation of advice given
	No documentation but parents recall advice

PICU paediatric intensive care unit; EMS emergency medical services

8.2 RESULTS

A total of 3212 modifiable factors were identified for the 282 children. More than half of the children had at least one major impacting modifiable factor in their pathway to care (Figure 8-1). The median number of major impact modifiable factors per child was 0.5 (IQR 0-3) whilst the median for moderate/minor impact factors was 6 (IQR 3-9) (Figure 8-2).

Table 8-4 gives the five most frequent modifiable factors (across all levels and including EMS) for each grade of impact. Five modifiable factors dominated the more than 477 factors which were considered to have a major impact on clinical outcomes. Two factors (inadequate initial assessment and/or interpretation of severity, and resuscitation not done or inadequate for shocked patient) accounted for 26% and three additional modifiable factors (circulatory issues, delay in critical care management, and accessibility of an emergency care area or personnel) for a further 6% each. Five moderate impact factors together accounted for 37% of all moderate impact factors (n=1826). These were ongoing monitoring and/or management while awaiting transfer (9%), referral delay (8%), inadequate explanations given to caregiver (8%), antibiotic therapy (6%), and delay in critical management decisions (5%).
For near miss there were low numbers but were predominantly hypoglycaemia management and airway issues, while lack of documentation was the predominant issue in the undefined category. Although documentation is (rightly) graded as an undefined impact, there was an important rate (almost half (44.5%) of undefined factors) of poor and missing documentation of key issues and missing dates, times and names.

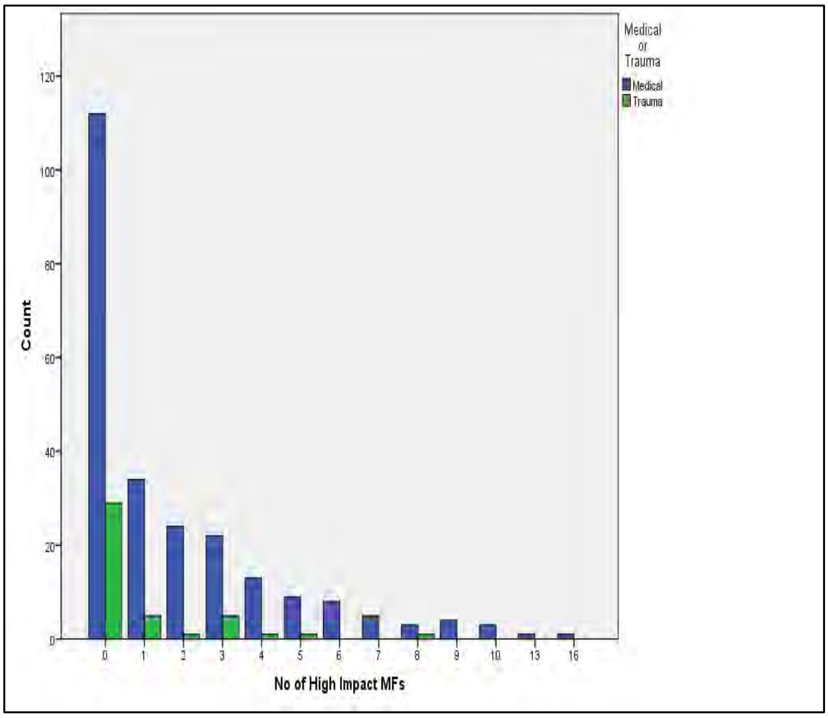


Figure 8-1 Number of major impact modifiable factors per case

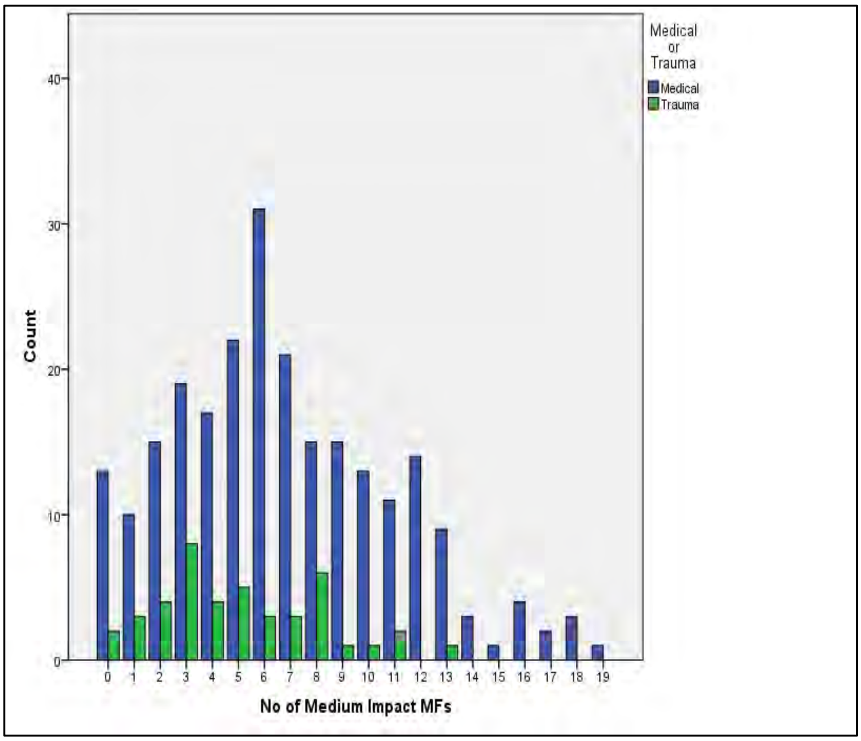


Figure 8-2 Number of moderate impact modifiable factors per case

8.2.1 Modifiable Factors and negative outcome

The most frequent high impact modifiable factors for each of the four main clinical review outcome variables (global quality of care, and avoidability of severity of illness, PICU admission and death) were examined (Table 8-5). The two most frequent high impact modifiable factors overall were also the two most frequent for negative cases for all four main outcome variables: Inadequate initial assessment and/or interpretation of severity, and resuscitation not done or inadequate for shocked patients. Nearly all the other frequent issues were similar across review elements: accessibility of EC area/ personnel, circulatory management, delay, and missing key findings.

Table 8-4 Most frequent modifiable factors at each impact level

Impact	Modifiable Factors	N	%
Major	INITIAL ASSESSMENT: Inadequate assessment/ interpretation of severity	62	13.0
	MANAGEMENT: Resuscitation not done/ inadequate for shocked patient	60	12.6
	MANAGEMENT: Circulatory issues	29	6.1
	MANAGEMENT: Delay in critical management decisions	28	5.9
	FACILITY: Accessibility of Emergency Care area/ personnel	28	5.9
	Total	**207/477***	**43.5**
Moderate/ Minor	REFERRAL: On-going monitoring/ management while awaiting transfer	172	9.4
	REFERRAL: Referral Delay	153	8.4
	COMMUNICATION: Explanation to caregiver	139	7.6
	MANAGEMENT: Antibiotic therapy	117	6.4
	MANAGEMENT: Delay in critical management decisions	91	5.0
	Total	**672/1826**	**36.8**
Near Miss	MANAGEMENT: Hypoglycaemia assessment and management	14	31.8
	MANAGEMENT: Airway Issues	10	22.7
	EMS: Inappropriate vehicle/ crew/ equipment	3	6.8
	FACILITY: Accessibility of Emergency Care area/ personnel	2	4.5
	INITIAL ASSESSMENT: Inadequate assessment/ interpretation of severity	2	4.5
	Total	**31/44**	**70.3**
No defined impact	DOCUMENTATION: Missing/poorly documented information	129	44.5
	DOCUMENTATION: Missing date/times	100	34.5
	TRIAGE: Inadequate assessment at triage	12	4.1
	EMS: Response time delay	7	2.4
	TRIAGE: Other - specify	5	1.7
	Total	**253/290**	**87.2**
Not Known	FACILITY: Accessibility of Emergency Care area/ personnel	52	9.0
	DOCUMENTATION: Missing/poorly documented information	28	4.9
	CONSULTATION: Senior review of patients (e.g. ward round) inadequate	27	4.7
	TRIAGE: Inadequate assessment at triage	26	4.5
	EMS: Communication with call centre at initiation of transfer	24	4.2
	Total	**157/575**	**27.3**

** Totals are the total number of modifiable factors for each impact factor*
***Major Impact** – factor which had clear negative impact on the outcome for the patient (worsened mortality or morbidity).*
***Moderate/ Minor Impact** – factor which on its own had minimal negative impact on the outcome **but** may have caused some morbidity and/ or extended the hospital/ PICU stay*
***Near Miss** - unplanned event that did not have major impact– but had the potential to do so. Only a fortunate break in the chain of events prevented an injury, fatality or damage*
***No defined impact** - factor which has no individual or cumulative negative impact on the outcome of this or future cases*
***Not known** - cannot be established or estimated given facts known about scenario*

Table 8-5 Major impact modifiable factors and negative clinical review outcomes

Global quality of care received poor			Severity of illness avoidable/potentially avoidable			PICU avoidable/potentially avoidable			Death avoidable/potentially avoidable		
Modifiable Factors	***N***	***%***	***Modifiable Factors***	***N***	***%***	***Modifiable Factors***	***N***	***%***	***Modifiable Factors***	***N***	***%***
Inadequate assessment/ interpretation of severity	39	16·7	Inadequate assessment/ interpretation of severity	48	13·3	Inadequate assessment/ interpretation of severity	28	16·5	Inadequate assessment/ interpretation of severity	17	16·2
Resuscitation not done/ inadequate for shocked patient	30	12·9	Resuscitation not done/ inadequate for shocked patient	46	12·7	Resuscitation not done/ inadequate for shocked patient	18	10·6	Resuscitation not done/ inadequate for shocked patient	11	10·5
Accessibility of Emergency Care area/ personnel	13	5·6	Delay in critical management decisions	21	5·8	Delay in critical management decisions	10	5·9	Circulatory management	8	7·6
Circulatory management	13	5·6	Accessibility of Emergency Care area/ personnel	21	5·8	Accessibility of Emergency Care area/ personnel	9	5·3	Missing key findings (history/ clinical)	6	5·7
Missing key findings (history/ clinical)	11	4·7	Circulatory management	20	5·5	Missing key findings (history/ clinical)	9	5·3	EMS: Response time delay	6	5·7
Delay in critical management decisions	10	4·3	Inappropriate vehicle/ crew/ equipment	17	4·7	Circulatory management	8	4·7	Delay in critical management decisions	5	4·8
Antibiotic therapy	9	3·9	Referral Delay	16	4·4	Referral Delay	7	4·1	Referral Delay	5	4·8
Total number of major impact factors	**233/477**	**48·9**	**Total**	**362/398**	**91·0**	**Total**	**170/386**	**44·0**	**Total**	**105/121**	**86·8**
PICU paediatric intensive care unit; EMS emergency medical services											

8.2.2 Modifiable Factors at each facility level

Further analysis gives the frequent modifiable factors for each facility level and EMS transfer type. Analysis of just the frequent modifiable factors (the top 10) was agreed as a reasonable approach, given the large number of modifiable factors, and the low frequencies after the first 10. Table 8-6 shows all the facilities, with much the same pattern, followed by Table 8-7 which shows the PHC facilities (GP, clinic and 24 hour CHC). At both the clinics and 24hr CHCs, five factors occurred in 10% of more of consultations: access to emergency care or personnel, inadequate triage, inadequate assessment/interpretation of severity, resuscitation not done or inadequate, and circulatory issues.

Table 8-6 Ten most frequent Modifiable Factors for all Facilities

All Facilities (n=612)			
MAJOR Modifiable Factors (top 10)	**N(% of top 10)**	**MODERATE Modifiable Factors (top 10)**	**N(% of top 10)**
Inadequate assessment/ interpretation of severity	59(21·4%)	Ongoing monitoring/ management while awaiting transfer	171(18·5%)
Resuscitation not done/ inadequate for shocked patient	59(21·4%)	Referral Delay	153(16·6%)
Delay in critical management decisions	28(10·1%)	Antibiotic therapy	117(12·7%)
Accessibility of Emergency Care area/ personnel	28(10·1%)	Delay in critical management decisions	91(9·8%)
Circulatory management	24(8·7%)	Delay in disposal decisions	78(8·4%)
Referral Delay	20(7·2%)	Inadequate assessment/ interpretation of severity	74(8·0%)
Antibiotic Therapy	17(6·2%)	Explanation to caregiver	72(7·8%)
Missing key findings (history/ clinical)	15(5·4%)	Accessibility of Emergency Care area/ personnel	71(7·7%)
Inadequate assessment at triage	15(5·4%)	Other - specify	53(5·7%)
Missed/ incorrect diagnosis	11(4·0%)	Inadequate assessment at triage	44(4·8%)

Table 8-7 Top 10 Modifiable Factors for Non Hospital Facilities (GP, clinic and CHC)

MAJOR Modifiable Factors (top 10)	N (% of top 10)	MODERATE Modifiable Factors (top 10)	N (% of top 10)
General Practitioner (n=22)			
Inadequate assessment/ interpretation of severity	8(26.7%)	Inadequate assessment/ interpretation of severity	4(16.7%)
Inappropriate referral mechanism (e.g. taxi/ private transport)	8(26.7%)	Inappropriate referral mechanism (e.g. taxi/ private transport)	3(12.5%)
Resuscitation not done/ inadequate for shocked patient	5(16.7%)	Communications with receiving facility	3(12.5%)
Missing key findings (history/ clinical)	2(6.7%)	Accessibility of Emergency Care area/ personnel	2(8.3%)
No consultation to offsite specialists	2(6.7%)	Missed/ incorrect diagnosis	2(8.3%)
Inappropriate referral destination	2(6.7%)	Explanation to caregiver	2(8.3%)
Delay in critical management decisions	1(3.3%)	Resuscitation not done/ inadequate for shocked patient	2(8.3%)
Antibiotic therapy	1(3.3%)	Missing key findings (history/ clinical)	2(8.3%)
Communications with receiving facility	1(3.3%)	No consultation to offsite specialists	2(8.3%)
-		Antibiotic therapy	2(8.3%)
City Health Clinic (n=57)			
Accessibility of Emergency Care area/ personnel	12(23.1%)	Accessibility of Emergency Care area/ personnel	15(18.8%)
Inadequate assessment at triage	10(19.2%)	Inadequate assessment at triage	11(13.8%)
Inadequate assessment/ interpretation of severity	8(15.4%)	Antibiotic therapy	11(13.8%)
Resuscitation not done/ inadequate for shocked patient	7(13.5%)	Ventilatory Issues	9(11.3%)
Circulatory issues	4(7.7%)	Explanation to caregiver	9(11.3%)
Missing key findings (history/ clinical)	3(5.8%)	Inadequate assessment/ interpretation of severity	8(10.0%)
Missed/ incorrect diagnosis	3(5.8%)	Missing key findings (history/ clinical)	5(6.3%)
Consultation inadequate	2(3.8%)	Delay in disposal decisions	4(5.0%)
Inappropriate referral mechanism (e.g. taxi/ private transport)	2(3.8%)	Communications with receiving facility	4(5.0%)
Investigations inadequate	1(1.9%)	Ongoing monitoring/ management while awaiting transfer	4(5.0%)
24 Hour CHC (n=103)			
Resuscitation not done/ inadequate for shocked patient	25(25.5%)	Antibiotic therapy	2(14.1%)
Inadequate assessment/ interpretation of severity	17(17.3%)	Inadequate assessment/ interpretation of severity	24(13.6%)
Circulatory issues	14(14.3%)	Explanation to caregiver	24(13.6%)
Accessibility of Emergency Care area/ personnel	10(10.2%)	Accessibility of Emergency Care area/ personnel	22(12.4%)
Missing key findings (history/ clinical)	6(6.1%)	Ongoing monitoring/ management while awaiting transfer	19(10.7%)
Delay in critical management decisions	6(6.1%)	Triage	15(8.5%)
Ongoing monitoring/ management while awaiting transfer	6(6.1%)	Missing key findings (history/ clinical)	14(7.9%)
Antibiotic therapy	5(5.1%)	Call/ information given to EMS about transfer	12(6.8%)
Referral Delay	5(5.1%)	Temperature management	11(6.2%)
Triage	4(4.1%)	Circulatory issues	11(6.2%)

Table 8-8 details the hospitals and Table 8-9 the RCWMCH facilities, with a similar pattern, 10% or more of cases found to have inadequate assessment/interpretation of severity, referral delays, delays in critical management decisions and antibiotic therapy.

Table 8-8 Top 10 Modifiable Factors for District and Regional Hospital Facilities (District and Regional Hospitals; RCWMCH: EC, Wards, Operating Theatre)

MAJOR Modifiable Factors (top 10)	N(% of top 10)	MODERATE Modifiable Factors (top 10)	N(% of top 10)
District Hospital (n=45)			
Resuscitation not done/ inadequate for shocked patient	7(27.0%)	Ongoing monitoring/ management while awaiting transfer	13(16.7%)
Inadequate assessment/ interpretation of severity	6(23.1%	Delay in disposal decisions	12(15.4%)
Delay in critical management decisions	3(11.5%)	Antibiotic therapy	9(11.5%)
Ventilatory Issues	2(7.7%)	Explanation to caregiver	8(10.3%)
Antibiotic therapy	2(7.7%)	Inadequate assessment/ interpretation of severity	7(8.9%)
Referral Delay	2(7.7%)	Accessibility of Emergency Care area/ personnel	7(8.9%)
Accessibility of Emergency Care area/ personnel	1(2.2%)	Referral Delay	6(7.7%)
Inadequate assessment at triage	1(2.2%)	Circulatory issues	6(7.7%)
Missing key findings (history/ clinical)	1(2.2%)	Analgesia	5(6.4%)
Investigations inadequate	1(2.2%)	Ventilatory Issues	5(6.4%)
Regional Hospital (n=50)			
Accessibility of Emergency Care area/ personnel	4(23.5%)	Delay in disposal decisions	8(15.1%)
Triage	2(11.8%)	Delay in critical management decisions	8(15.1%)
Inadequate assessment/ interpretation of severity	2(11.8%)	Ongoing monitoring/ management while awaiting transfer	7(13.2%)
Missed/ incorrect diagnosis	2(11.8%)	Accessibility of Emergency Care area/ personnel	5(9.4%)
Delay in critical management decisions	2(11.8%)	Other - specify	5(9.4%)
Antibiotic therapy	2(11.8%)	Antibiotic therapy	5(9.4%)
Inadequate assessment at triage	1(5.9%)	Call/ information given to EMS about transfer	4(7.6%)
Airway Issues	1(5.9%)	Inadequate assessment at triage	4(7.6%)
Referral Delay	1(5.9%)	Airway Issues	4(7.6%)
-		Ventilatory Issues	3(5.7%)

Table 8-9 Top 10 Modifiable Factors for RCWMCH Facilities (EC, Wards, Operating Theatre)

MAJOR Modifiable Factors (top 10)	N(% of top 10)	MODERATE Modifiable Factors (top 10)	N(% of top 10)
RCWMCH Emergency Centre (n=241)			
Resuscitation not done/ inadequate for shocked patient	11(18.9%)	Ongoing monitoring/ management while awaiting transfer	106(23.9%)
Referral Delay	11(18.9%)	Referral Delay	97(21.8%)
Inadequate assessment/ interpretation of severity	9(15.5%)	Antibiotic therapy	51(11.5%)
Delay in critical management decisions	7(12.0%)	Delay in critical management decisions	47(10.6%)
Antibiotic therapy	4(6.8%)	Delay in disposal decisions	34(7.6%)
Delayed consultation	4(6.8%)	Triage	27(6.0%)
Inappropriate referral destination	4(6.8%)	Explanation to caregiver	23(5.1%)
Ongoing monitoring/ management while awaiting transfer	4(6.8%)	Delayed consultation	23(5.1%)
Missing key findings (history/ clinical)	2(3.4%)	Inadequate assessment/ interpretation of severity	19(4.2%)
Airway Issues	2(3.4%)	Accessibility of Emergency Care area/ personnel	16(3.6%)
RCWMCH Ward (n=74)			
Inadequate assessment/ interpretation of severity	8(26.7%)	Referral Delay	35(28.0%)
Delay in critical management decisions	8(26.7%)	Delay in critical management decisions	25(20.0%)
Resuscitation not done/ inadequate for shocked patient	3(10.0%)	Ongoing monitoring/ management while awaiting transfer	22(17.6%)
Circulatory issues	2(6.7%)	Delayed consultation	8(3.2%)
Blood Sugar assessment and management	2(6.7%)	Delay in disposal decisions	8(3.2%)
Antibiotic therapy	2(6.7%)	Ventilatory Issues	6(4.8%)
Delay in disposal decisions	2(6.7%)	Inadequate assessment/ interpretation of severity	6(4.8%)
Investigations inadequate	1(3.3%)	Antibiotic therapy	6(4.8%)
Temperature Management	1(3.3%)	Senior review of patients (e.g. ward round) inadequate	5(4.0%)
Electrolyte abnormality Management	1(3.3%)	Circulatory issues	4(2.4%)
RCWMCH Operating Theatre (n=29)			
Anaesthetic technique	1(100.0%)	Delay pre-op	6(50.0%)
-		Anaesthetic Pre-op Assessment Inadequate	2(16.7%)
		Anaesthetic technique	1(8.3%)
		Airway Issues	1(8.3%)
		Surgical Pre-op Assessment Inadequate	1(8.3%)
		Surgical technique	1(8.3%)

8.2.3 Modifiable Factors for EMS transfers

Table 8-10 gives the main modifiable factors for EMS transfers, divided into the different categories of transfers and overall. The predominant issues relate to inappropriate vehicle/ crew which is likely a dispatch issue, and delays in EMS response time. It is also clear that children were not always optimally assessed and stabilized prior to transfer. An additional important concern coming out of the parent interviews is that EMS personnel were general remiss in explaining to caregivers what they were doing and what was happening to their child.

Table 8-10 Top 10 Modifiable factors identified for each type of EMS transfer

EMERGENCY MEDICAL SERVICES			
MAJOR Modifiable Factors (top 10)	**N(% of top 10)**	**MODERATE Modifiable Factors (top 10)**	**N(% of top 10)**
Primary (Home/ Scene) (n= 57 transfers)			
Inappropriate vehicle/ crew/ equipment	4(30.8%)	Inappropriate vehicle/ crew/ equipment	26(31.3%)
Circulatory issues	2(15.4%)	Inadequate assessment before transfer	13(15.7%)
Response time delay	2(15.4%)	Inadequate stabilization for transfer	9(10.8%)
EMS disposal decision	1(7.7%)	Inadequate assessment/ interpretation of severity	7(8.4%)
Inadequate assessment/ interpretation of severity	1(7.7%)	Explanation to caregiver	6(7.2%)
Inadequate assessment at triage	1(7.7%)	EMS disposal decision	5(6.0%)
EMS: Inadequate assessment before transfer	1(7.7%)	Inadequate monitoring en route	5(6.0%)
Other	1(7.7%)	Analgesia	4(4.8%)
		Dispatch time delay	4(4.8%)
		Ventilatory Issues	4(4.8%)
Interfacility Transfer (non PFS) (n= 143 transfers)			
Inappropriate vehicle/ crew/ equipment	12(25.0%))	Explanation to caregiver	52(22.8%)
Response time delay	12(25.0%))	Inappropriate vehicle/ crew/ equipment	37(16.2%)
Inadequate stabilization for transfer	7(14.6%)	Inadequate monitoring en route	35(15.4%)
Dispatch time delay	5(10.4%)	Inadequate assessment before transfer	27(11.8%)
Inadequate assessment before transfer	3(6.3%)	Response time delay	26(11.4%)
Communication with call centre at initiation of transfer	3(6.3%)	Temperature management	13(5.7%)
Circulatory issues	2(4.2%)	Communication with call centre at initiation of transfer	12(5.3%)
Inadequate assessment/ interpretation of severity	2(4.2%)	Ventilatory Issues	11(4.8%)
Transfer time excessive	1(2.1%)	Transfer time excessive	8(3.5%)
Inadequate monitoring en route	1(2.1%)	Inadequate stabilization for transfer	7(3.1%)
Paediatric Flying Squad (n= 36 transfers)			
Response time delay	5(25.0%)	Response time delay	15(37.5%)
Blood-sugar assessment and management	3(15.0%)	Transfer time excessive	6(15.0%)
Inadequate stabilization for transfer	3(15.0%)	Explanation to caregiver	5(12.5%)
Inadequate assessment before transfer	2(10.0%)	Temperature management	3(7.5%)
Inappropriate vehicle/ crew/ equipment	2(10.0%)	Inadequate monitoring en route	3(7.5%)
Airway Issues	1(5.0%)	Inadequate assessment before transfer	2(5.0%)
Ventilatory Issues	1(5.0%)	Communications with receiving facility	2(5.0%)
Circulatory issues	1(5.0%)	Blood-sugar assessment and management	2(5.0%)
Communications with receiving facility	1(5.0%)	Inappropriate vehicle/ crew/ equipment	1(2.5%)
Dispatch time delay	1(5.0%)	Ventilatory Issues	1(2.5%)
Overall Emergency Medical Services (n=292 transfers)			
Inappropriate vehicle/ crew/ equipment	20(25.6%)	Explanation to caregiver	67(19.6%)
Response time delay	19(24.4%)	Inappropriate vehicle/ crew/ equipment	65(19.0%)
Inadequate stabilization for transfer	10(12.8%)	Inadequate monitoring en route	44(12.9%)
Inadequate assessment before transfer	6(7.7%)	Response time delay	43(12.6%)
Dispatch time delay	6(7.7%)	Inadequate assessment before transfer	43(12.6%)
Circulatory issues	5(6.4%)	Temperature management	18(5.3%)
Communication with call centre at initiation of transfer	4(5.1%)	Ventilatory Issues	17(5.0%)
Blood-sugar assessment and management	3(3.9%)	Inadequate stabilization for transfer	17(5.0%)
Inadequate assessment/ interpretation of severity	3(3.9%)	Inadequate assessment/ interpretation of severity	14(4.1%)
Inadequate monitoring en route	2(2.6%)	Transfer time excessive	14(4.1%)

8.3 Discussion

The most frequent clinical failings were in the areas of assessment and initial resuscitation of the acutely ill child, compounded by delays in decision making and referral. It is noteworthy, and validates the review processes that the same modifiable factors were prevalent for each of the negative review issues – poor quality of care; avoidable PICU admission, avoidable severity and avoidable death.

Apart from these repeated findings, there were noticeable differences in the modifiable factors at different facility levels. For GPs, although numbers were low and data limited, referrals were frequently made by inappropriate means (e.g. private or public transport rather than EMS commonly), and to inappropriate destination facilities (commonly nearest facility regardless of resources/ context). This would seem to show a pattern of limited knowledge and integration between private sector GP services and public sector services, as well as under-use of EMS by GPs. Clinics (nurse led and daytime only) showed issues with access barriers to being seen by a health care professional, with long waits and emergency patients undifferentiated from elective cases, and this overlapped with the lack of triage – the clinics had no triage system in place, any selection or prioritization of urgent or ill patients was made subjectively, if at all. At the CHCs, they saw enough critical paediatric illness to maintain competency, yet overwhelmingly they underestimated severity, and even when severity was recognized, were not aggressive enough in their resuscitation, especially around management of circulatory collapse and shock (practitioners often failed to obtain adequate IV access, seldom performed IO, and then rarely gave more than a single 10- 20 ml/ kg bolus). Despite mandated triage systems, access was still a problem (long queues, not always separated from adults, and often no clear direction as to where and how to get emergency help within a facility). Explanation to caregivers was often inadequate, and once seen and initial management and referral had been done, children were often left unmonitored and unmanaged awaiting transfer.

Once children reached a hospital level facility there were overall less issues and modifiable factors (in line with increasing quality of care as judged by reviewers (and caregivers)). The top two issues of inadequate resuscitation and underestimation of severity remained, although in much lower numbers. At these facilities children would generally have been seen or reviewed by an experienced doctor or specialist at urban facilities, and given the higher frequency of critical presentations, these practitioners would be more familiar with paediatric assessment and management. Specific issues in the district hospital included delays in decision making (decision to refer usually), issues with ventilation (often related to lack of equipment or unfamiliarity with it for children) and delay or incorrect drug/ dose for antibiotics. Regional hospitals had no major modifiable of inadequate resuscitation which is a positive finding, but otherwise were similar to district hospitals. At RCWMCH EC, with dedicated high flow paediatric emergencies, recognition and resuscitation of children should not be an issue, but this was not always the case, one or both of these issues were present in 20/241 (8.3%) of cases. The main concerns at RCWMCH EC were referral delay and monitoring – usually while awaiting a PICU bed.

Several studies have looked at the care of critically ill children in well-resourced settings. Nadel[235] and Ninis[236] looked at meningococcaemia and identified recognition and management of seriously ill children as key issues; Launay[237] looked at severe bacterial infection with similar findings. ChIP SA[312] looked at childhood deaths in health facilities and identified late presentation, poor initial emergency care (especially poor initial assessment and insufficient recognition of severity), poor communication with the referring institution, inadequate HIV management, and limited access to PICU as critical issues. This is discussed and compared to the literature in more detail in the main discussion, chapter 10.

9 STANDARDS FOR PAEDIATRIC EMERGENCY CARE IN CAPE TOWN

"*The primary motivating force for standards development by emergency physicians has been the desire to establish an acceptable level of care within the specialty, followed by the growing emphasis on quality assessment and quality improvement, the measurement of which requires an existing standard of care*."[314] *Cantrill 1992*

"*Performance according to standards is the cornerstone of quality assurance in healthcare and the end result inspiring many quality assurance activities*."[315] *Marquez 2001*

9.1 BACKGROUND

Internationally there is a drive towards quality assurance as a driver of improvement and monitoring of health care.[316,317] Measures of the quality of health care can be divided into structure, process and outcome[318], but these standards will focus on process measures. The initial step in this process is the translation of guidelines and protocols into standards which can be used to measure performance (defined in Box 1[319]). Another more practical definition is given by Marquez: "standards are explicit statements of expected quality in the performance of a healthcare activity"[315]

BOX 1: DEFINITIONS OF KEY CONCEPTS (Campbell 2003)[310]:

- Guidelines – aid clinical decision making
- Protocols – criteria defining interventions steps required
- Quality Indicator – measurable element of practice performance (based on evidence/ consensus)
- Performance Indicator – measurable device to monitor care
- Standard – level of compliance with indicator (whether set prospectively as a goal to meet, or measured retrospectively to determine compliance/ adherence with standard)

Standards for emergency paediatric care have developed rapidly in the UK and USA, with clear signs that they are useful not only for quality assurance, but also as drivers for change and improvement[47](personal communication F. Davies, 2013). There is an urgent need for such standards in LMIC where the burden of childhood mortality remains and standards could provide not only a goal for clinicians and managers, but a rapid and easy assessment of their performance in different areas.[320]

The PTC study was the initiator for the development of key standards for the management and referral of critically ill and injured children in Cape Town. It was thought that explicit, practical and achievable standards, developed by all role-players, would lend an objective measure to the assessment of the quality of care in the system, with the insight that many of the outcomes and assessments from the study would be subjective, however rigorous the expert review process. Subsequent to this process, the International Federation of Emergency Medicine (IFEM) has published a set of standards for paediatric emergency care which go a long way towards this goal, but are perhaps not specific enough for individual contexts.[321,322] Following the PTC standards work, a Provincial Taskforce was commissioned to expand the critical care standards from this work, into a comprehensive set of Standards for Paediatric Emergency Care for the Western Cape Province, which are in an advanced stage of review by provincial role-players (personal communication B. Cheema, 2014).

This chapter outlines the development of consensus standards for paediatric emergency care, as well as providing compliance data with these standards from the research project.

9.2 DEVELOPMENT OF CONSENSUS STANDARDS

A provincial paediatric standards taskforce was convened by the clinical managers in paediatrics and EM in the Western Cape in March 2011 to develop a set of standards for paediatric emergency care. A formal consensus methodology would have been to use a Delphi technique – *i.e.* identification of issues by a panel of experts, and then several rounds of the panel rating the importance of each issue until predefined consensus was developed. This formal technique has its value, but is slow, and not necessarily superior to a less didactic approach.[323-325] An accelerated nominal group process,[323] was thus chosen, with the insight that these standards would not be for widespread clinical circulation and use, but for the research process and ideally for further development at a later stage into more comprehensive and universal standards for the province. The process conducted was:

i. Selection of a representative panel of participants
ii. Identification of common and important issues from other standards resources, and through a workshop process to use the experience and knowledge of the panel to identify key standards
iii. Drafting of standards and circulation amongst the panel for review and comment
iv. Detailed panel discussion of each standard to exhaustively review and refine each standard

Panel members were identified and invited, with representation from all involved disciplines and levels of care (Table 9-1). The panel members included experts (senior personnel), clinicians, and managers, all with enough credibility to give the process and the outcomes value.

Table 9-1 Provincial Emergency Care Standards Taskforce Composition

Profession	Speciality/ Working Environment	Number of representatives	Total (33)
Doctors:	Emergency Medicine	6	15
	Paediatrics	5	
	Trauma	1	
	Family Medicine	3	
Nursing	Tertiary Hospital	6	16
	District/ Regional Hospital	3	
	Primary Health Care	3	
	Training	3	
	Management	1	
EMS	Quality Assurance	2	2

It was agreed that standards would be based on available resources and international standards, but practical and achievable in the local context. They would focus on emergency conditions commonly requiring critical care (*i.e.* culminating in PICU admission), be applicable to all levels of health delivery and would enable objective measurement of the quality of care delivered.

Available resources which the taskforce used to shape and define the standards included local guidelines, protocols, and policies; as well as international standards, textbooks and publications.[224,244,326-331]

BOX 2: CLASSIFICATION OF STANDARDS

1. Structure & Equipment
2. Reception & Triage Process
3. Documentation
4. Standards for Tertiary Hospital/ ICU Referrals
5. Gastro-Enteritis
6. Respiratory Distress
7. Fever/ Septic Shock/ Meningitis
8. Convulsions & Coma
9. Trauma & Burns

A series of three monthly taskforce meetings were held, with email communication between all parties throughout. At the initial meeting, the composition of the standards was established by several subgroups tasked with identifying key standards from their discussions. These were presented to the whole group, debated and refined for local services, and clarified into a draft consensus document which was circulated via email to all members of the taskforce for input and comment. Subsequent meetings refined and strengthened each standard with input from all. Standards were classified broadly into structural issues relating to a facility; general issues around reception and referral of a patient, and then by each of the common presenting critical illness or injury types identified (Box 2). Consensus was strong for the majority of standards, but there were contentious issues, especially around triage (there being several systems in use in the metropolis at present and a parallel taskforce developing and validating a universal revised paediatric triage system;[67,154] and referral policies for paediatric trauma which many panellists were concerned is unclear.

Various local guidelines, protocols and policies were reviewed and elements of these were integrated and referred to. These included: SATS[151], Western Cape Gastro-Enteritis policy [89], PFS policy and criteria,[332,333] Emergency Medicine Society of South Africa (EMSSA) Resuscitation Trolley Guidelines,[334, 335] South African Burns Society Guidelines and Criteria,[336], EMS DeMist handover system,[337] and local checklists for receiving facilities for paediatric referrals. In addition EMS delegates to the taskforce developed draft EMS standards in the same structure as the general guidelines and these were reviewed and integrated by the panel.

Of note, for the first section detailing the structure and equipment required, the EMSSA Guidelines for Resuscitation Trolleys and Emergency Centre Equipment were accepted verbatim as it was deemed beyond the accelerated consensus process to develop equipment lists.[327,334,337] The process and documentation sections were somewhat idealistic for some settings, for example staffing criteria and timelines, although the panel were in agreement that these were completely feasible in the short term and should be in place. The full set of standards was separated into facility and EMS standards for each of the five main presentations covered. ***Appendix XI*** gives the comprehensive standards outcome from the process. These standards were by no means comprehensive, merely presenting a starting point for standards and for the quality assurance purposes of this study.

In order to facilitate the use of these standards for the research project, the standards were condensed by selection of key standards that could be assessed in a binary way, whether they were they met or not, and those that could feasibly be assessed from documented medical records. Reliance on documentation was likely to be a flaw in this assessment, but strengthened by a lay version of events as related by the caregiver to supplement the timeline and process, and for the research purposes assumptions would be made for standards that were not fully documented if there was good evidence that they were met. For example a child with minimal documentation of management or timelines at a facility (not even documenting IV access or oxygen administration); and then transferred by a basic life support (BLS) EMS crew who documented that the child had an IV line and oxygen face mask on their arrival. With the mother who accompanied the child confirming an IV line was administered and an oxygen face mask applied at the facility; this confirm that the IV and oxygen standards were met. The documentation of each standard was noted in the data collection tool. Standards around structure, equipment and staffing were excluded as they could not be assessed from the information available.

Once condensed for the research tool, each standard was graded and classified by the consensus of three international paediatric EM experts (AA, LW, IM) (consensus by two rounds of the document circulated by email to all three with open comments and discussion) into three grades of standards. This was done to enable comparison of standards of clinically similar magnitude (to avoid comparing for example airway management with documentation of airway management). They were:

- critical standards (life threatening essential issues of absolute and time critical importance),
- important standards (issues that need to be addressed but perhaps without the acuity and clear link to outcome of individual cases),
- Necessary standards (issues such as documentation and classification that are necessary in the system but have less impact on individual outcome)

This condensed and graded tool, was used to assess compliance in the study, comprising 218 consensus standards for multilevel paediatric emergency care of common critical illness and injuries divided into those for health facilities, and those for EMS as shown in Table 9-2. Only applicable standards were assessed at each level and for each dominant presentation.

Table 9-2 Condensed and Graded Standards for Paediatric Critical Care

STANDARDS	CRITICAL	IMPORTANT	NECESSARY
FACILITY STANDARDS			
1. GENERAL/ TRIAGE	Entry to facility - eyeball assessment <5 min	Fast track for paediatrics	
	Triage system in use	Triage YELLOW –manage < 60 min	
	Triage RED - managed by senior HCP (IMMED)	Retriage if Unseen in 2 hrs	
	Oxygen therapy Red < 5 min	Analgesia < 20 min	
	Triage ORANGE < 10 min)		
2. DOCUMENTATI ON		Doc weight	Doc time arrival
		Doc time seen by HCP	Doc time triage/ first assessed
		Doc time Rx commenced	Doc time date each assess/treat
			Doc HCW name
3. GASTRO	Gastro HGT at initial assessment (IMMED)	Oral Rehydration Area in facility	
	Oxygen to Shocked Gastro (IMMED)	<=5% given ORS and reassess	
	Doc of signs and severity	Fails ORS @ 2 hrs then NGT	
	ID and Doc signs shock	Well-nourished 20 ml/kg of 1/2 DD IV	
	Oxygen admin if >= 10% clinically dehydrated	Malnourished NGT 10 ml/kg/hr	
	HGT check and manage if >=10% clinically dehydrated	Shock: Unstable site IV/IO then NG 30ml/kg/hr	
	IV or IO access		
	Shock manage 20ml/kg NS repeated		
	Shock: HGT check and manage		
	Shock:2nd IV bolus and look cause		
	Shock: 3rd IV bolus and call help		
	Oxygen to all shocked		
4. RESPIRATORY	Airway Management (IMMED)	Airway: Performed by competent HCP ASAP	Croup: Steroid prescription
	ID and doc of problem airway	ETT correct size and depth	Pneumonia: Classification mod/sev/v sev
	BVM as alternative	ETT confirmation placement	Asthma: Dose of steroid/ b dilator
	ID and doc of severity respiratory distress	Ventilator setup correct	Asthma: Discharge information/ checks

STANDARDS	CRITICAL	IMPORTANT	NECESSARY
	Basic Airway manoeuvres	Post intubation care (5 min)	
	Oxygen to all sats <92 or other signs	Documentation Advanced Airway Management	
	Croup: Adrenaline nebs	Croup: Doc signs severity	
	Severe Pneumonia Assessment -Abics (30 min)	Pneumonia: Doc signs pneumonia severity	
	Pneumonia: IV appropr antibiotics in 30 min	Pneumonia: Dose antibiotics correct	
	Asthma triage- nebs (5 min)	Asthma Doc signs severity	
		Asthma: Nebulize b/dilator < 5 min	
		Asthma: Steroid administration	
5. FEVER/ SEPTIC SHOCK	Fever -Abics within 60 min	Doc evidence meningitis	Fever temp at triage (IMMED)
	Septic Shock triage-IV bolus <10 min	Inotropes/ vasopressors if unresponsive	Fever T >38,5- antipyretic (30 min)
	Septic Shock triage-Abics <30 min	Urine testing (if <3/12 or no obv cause)	Temperature documented at triage
	Early recognition septic shock	Referral of s/shock to appropriate facility(PICU)	
	ID and Doc SHOCK		
	IV IO access early		
	HGT Mx (check and treat as appropriate)		
	Appropriate Abic given IV/IM		
6. COMA/ CONVULSIONS	Coma/ Convuls - HGT Mx (IMMED)	ID and Doc Level of Consciousness (GCS/AVPU)	Neonatal Convulsion: phenobarbitone
	Airway Manoeuvres as appropriate	Convulsion: Anticonvulsant dose correct	Convulsion: BZD x 2 if failure then phenytoin/ phenobarbitone
	Oxygen administered	Coma: Neuro-observations	
	Convulsion: Anticonvulsant given appropriate route	Convulsion: Post convulsion - Mx	
	Coma: Brain imaging referral	Coma: Anticonvulsant as appropriate	
	Coma: Referral facility as appropriate		
7. TRAUMA	IV/ IO insertion if signs shock (IMMED)	Trauma Assess- Analgesia (ASAP)	Remain with parent/ carer
Polytrauma (PT) **Head Injury (HI)**	Bolus IV/IO fluid to shocked pt (IMMED)	PT Analgesia Mx	PT: NPO
Orthopaedics (Ortho)	PT: Bolus 10 ml/kg IV RL or NS ASAP	PT Spinal Immobilization	
Burns	HI: CT Brain required ID and expedite	PT Blood transfusion after 40ml/kg (30 min)	

STANDARDS	CRITICAL	IMPORTANT	NECESSARY
	HI Airway manoeuvres as appropriate	HI Head Injury document GCS IMMED (ASAP)	Ortho :Procedural Sedation all interventions
	HI Intubation where indicated and appropriate	HI ID and Doc Level of Consciousness (20 min)	Documentation of burn wound : 1. region; area of burn % 2. Depth of burn 3. Time of burn 4. Mechanism of burn
	HI Transfer appropriate as per HI Guidelines	HI BVM as an alternative	
	HI Neurosurgical review ASAP	HI Neuro-observation	
	BURN: IV fluids as per Parklands 3.5xWTx%	Ortho: Immobilization and reduction fractures ASAP	
	BURN: Search inhalation burns	Ortho: Open #/complicated wound – Abics < 30 min	
	BURN: Inhalation Burns – early intubation	Severe Burns - Occlusive Dressing (ASAP)	
		Burns: Analgesia severe burns <20 min	
		Burns: Mx according to SABSG <2 hrs	
		Burns: Escharotomy where appropriate	
		Burns: Referral as per SABSG or RCWMCH Burns criteria	
		PT: NAI consideration	
		PT: ATT open wounds	
8. Referral		Early EMS contact by PHC/ CHC level	Referral letter contents
		Referral communications for critical paeds	
		Acceptance of any critical child by L2/3	
		EMS communication to rec facility	
		Facility handover to/from EMS	
9. ICU Referral	ICU request to ICU assessment	ICU request (non-ventilated) to ICU bed (4 hrs)	Monitoring Ventilated/ Critical Patient: nurse ratio 1:1
	ICU request (ventilated) to ICU bed	Specialist consult/review when necessary (< 15 min)	Monitoring of vitals every 15 m
	Maximum ventilation outside PICU (24rs)	Monitor/ventilatory equipment outside ICU	
EMS STANDARDS			
STANDARD	**CRITICAL**	**IMPORTANT**	**NECESSARY**
1. GENERAL	P1 Calls EMS call-scene (15 min)	EMS route child to closest appropriate facility	Referral communications for critical paediatrics

STANDARDS	CRITICAL	IMPORTANT	NECESSARY
	Arrival to Oxygen for RED (IMMED)		EMS communication to receiving facility
	Triage system in use		EMS handover receiving/ destination facility
	EMS SATS RED treated by ALS		
	EMS Paediatric appropriate resus equipment		
	EMS PFS for interfacility red transfer		
	EMS ALS if no PFS		
2. EMS DOCUMENTATION	Acceptance of any critical child L2/3	Doc time call received	
		Doc time EMS team dispatched	
		Doc time arrival	
		Doc EMS time depart scene/referring facility	
		Doc EMS time destination facility	
		Doc EMS management	
		Doc EMS HCW name	
3. EMS GASTRO	Gastro HGT at initial assessment (IMMED)	Doc of signs and severity	
	Oxygen to Shocked Gastro (IMMED)	Well-nourished 20 ml/kg 1/2 DD IV bolus	
	ID and Doc signs shock	2nd IV bolus and look cause	
	Oxygen admin if >=10% clinically dehydrated	3rd IV bolus and call help	
	HGT check and Mx if >=10% clinically dehydrated		
	Shock: IV or IO access		
	Shock Mx 20ml/kg NS repeated		
4. EMS RESPIRATORY	SHOCK:HGT check and Mx	Asthma assessment - nebs (5min)	ETT correct size and depth
	ID and Doc of Respiratory Distress	ETT confirmation placement	Ventilator setup correct
	Basic Airway Manoeuvres		Post intubation care
	Oxygen to all appropriate		
5. EMS FEVER/ SEPTIC SHOCK	Airway: Performed by competent HCP ASAP		
	BVM as alternative		
	Septic Shock triage-IV bolus (10min)		Documentation Advanced Airway Mx
	Early recognition of septic shock		

STANDARDS	CRITICAL	IMPORTANT	NECESSARY
	ID and Doc SHOCK		
	IV IO access early		
6. EMS COMA/CONVULS	HGT Mx (check and treat as appropriate)	ID and Doc Level of Consciousness(GCS/AVPU)	
	Coma/ Convulsion HGT Mx (IMMED)	Convulsion: Anticonvulsant given appropriate route	Post convulsion Mx
	Airway Manoeuvres as appropriate	Conv: Anticonvulsant dose correct	
	Oxygen administered	Conv: ID and Doc Level of Consciousness	
		Conv: Airway Manouevres as appropriate	
		Coma: Anticonvulsant as appropr	
		Coma: Neuro-observations	
7. EMS TRAUMA **Polytrauma (PT)** **Head Injury (HI)** **Orthopaedics (Ortho)** **Burns**	IV/ IO insertion if signs shock (IMMED)	Trauma Assessment- Analgesia (10 min)	PT: Remain with parent/ carer
	Bolus IV/IO fluid to shocked patient (IMMED)	Head Injury documentation GCS (IMMED)	Burns: Documentation of burn wound : 1.region; area of burn % 2.Depth of burn 3.Time of burn 4.Mechanism of burn
	PT: Bolus 10 ml/kg IV R/L or N/S ASAP	Severe Burns - Occlusive Dressing (10 min)	
	HI: Airway manoeuvres as appropriate	PT: Spinal Immobilization	
	HI: BVM as an alternative	HI: Head Injury documentation GCS (IMMED)	
	HI: Intubation where indicated and appropriate	HI: ID and Doc Level of Consciousness	
	HI: Transfer appropriate as per HI Guidelines	Ortho: Immobilization and reduction fractures ASAP	
		Severe Burns – Occlusive. Dressing (ASAP)	
		Analgesia severe burns (20 min)	

 # fracture; Abics antibiotics; ALS advanced life support; ATT anti tetanus toxoid; AVPU awake/ verbal response/ pain response/ unresponsive scale; BVM bag valve mask; CHC community health centre; Doc document; EMS emergency medical services; ETT endo-tracheal tube; Gastro gastroenteritis ; GCS Glasgow come scale; HCP health care provider; HGT haemo-glucose test; HI head injury; ICU intensive care unit; ID identification; IO intra-osseous; IV intra venous; Mx management; NAI non accidental injury; Neb nebulizer; NG naso-gastric; NPO nil per os; NS normal saline; ORS oral rehydration solution; PFS paediatric flying squad; PHC primary health care; RL ringers lactate; Rx treatment; SABSG South African Burns Society Guidelines ; Sats saturation (pulse oximetry)

9.3 RESULTS: SYSTEM WIDE COMPLIANCE WITH STANDARDS

Data were collected from relevant medical records for each facility and EMS transfer involved in the emergency care of each child, and through a semi-structured interview with the caregivers of these children. As part of the clinical review process, the compliance with each of the relevant consensus standards was assessed. In some cases due to poor (or lack of) documentation, the standards were assessed from the interview data, or from prior or retrospectively documented information (for example whether oxygen was delivered or IV fluid administered/ time delays when not documented by a practitioner were often given by the caregiver, or failing that the presence of an IV on arrival at the subsequent facility/ EMS arrival would indicated IV access had been obtained). The standards compliance is presented here to show the system wide compliance with these consensus standards and how they may be used to monitor and target improvements.

There were 613 facility visits and 291 EMS transfers (total 904) where standards were assessed. Each of the applicable process standards (excluding the structure and equipment and staffing elements which were beyond the resources of this study to capture and will likely require a subsequent environmental scan, perhaps targeted at problem sites/ levels as this data suggests) were applied to the 613 facilities visited (excluding operating theatre and PICU) and the 291 EMS transfers (Table 9-3). A total of 19,119 standards were applied. A variable number of standards were applied to each site/transfer dependent on the context, diagnosis and information available, with a mean of 21.1 standards applied to each with a consistent range across most facilities, except the GPs and private hospitals where access to records was limited often to a referral letter only, so less information was available.

Overall standards were met in 73.1% of the 13,572 standards in 613 consultations at health care facilities, and at 82.3% of the 5547 standards in 291 EMS contacts. Compliance with standards increased from PHC sites through to hospital based sites and specialist services as shown in Table 9-3 and graphically in Figure 9-1. Compliance with all standards, as well as critical and important standards were generally higher for all types of EMS contacts, than health care facility contacts.

Additional information from the standards compliance for different categories of standards (classified by patient presentations) (Table 9-4) relates issues specific to those areas and diagnoses. General/triage standards were poorly met both in facilities (important standards met=39.2%) and in EMS (critical standards met =14.3%). Gastro/shocked standards also had low compliance for EMS transfers.

Table 9-3 Standards Compliance across levels of facilities and EMS types

Facility	% Critical Standards Met#	% Important Standards Met#	% Necessary Standards Met#	% All Stds Met$	*TOTAL STDS APPLIED*	*Stds applied per facility/EMS visit*
GP (n=22)	26.8	17.6	28.6	23.5	*179*	*8.1*
CHC 24hr (n=106)	69.9	61.1	69.4	66.2	*2502*	*23.6*
Clinic (n=53)	49.8	57.7	41.3	50.9	*1016*	*19.2*
District Hospital (n=45)	77.5	72.7	73.3	74.4	*1090*	*24.2*
Regional Hospital (n=50)	86.9	84.4	78.8	84.0	*1328*	*26.6*
Private Hospital (n=11)	79.2	73.2	76.0	76.1	*134*	*12.2*
RCWMCH EC (n=239)	84.4	78.2	65.7	77.5	*5702*	*23.9*
RCWMCH Ward (n=76)	89.8	81.4	67.1	79.6	*1452*	*19.1*
Other (n=11)	48.0	77.0	44.0	56.8	*169*	*15.4*
All Facilities (n=613)	**79.0**	**72.4**	**65.6**	**73.1**	***13572***	***22.1***
EMS - Home (n=33)	63.1	95.2	62.3	79.0	*539*	*16.3*
EMS - Scene (n=32)	73.4	88.4	57.0	78.3	*609*	*19.0*
Inter-facility (n=170)	72.9	93.6	63.2	81.0	*3179*	*18.7*
PFS (n=42)	90.0	93.5	67.9	87.8	*966*	*23.0*
Flight (n=14)	89.4	94.6	95.9	92.9	*254*	*18.1*
All EMS (n=291)	**76.0**	**93.2**	**65.5**	**82.3**	***5547***	***19.1***
OVERALL (n=904)	**78.0**	**79.2**	**65.6**	**75.7**	***19119***	***21.1***

Stds standards; GP general practitioner, CHC community health centre, EC - emergency centre, PICU - paediatric intensive care unit, RCWMCH - Red Cross War Memorial Children's Hospital; EMS emergency medical services (ambulance); PFS paediatric flying squad;

 # % met calculated by number of stds met/ (stds met + stds not met) % i.e. % of all stds applied.

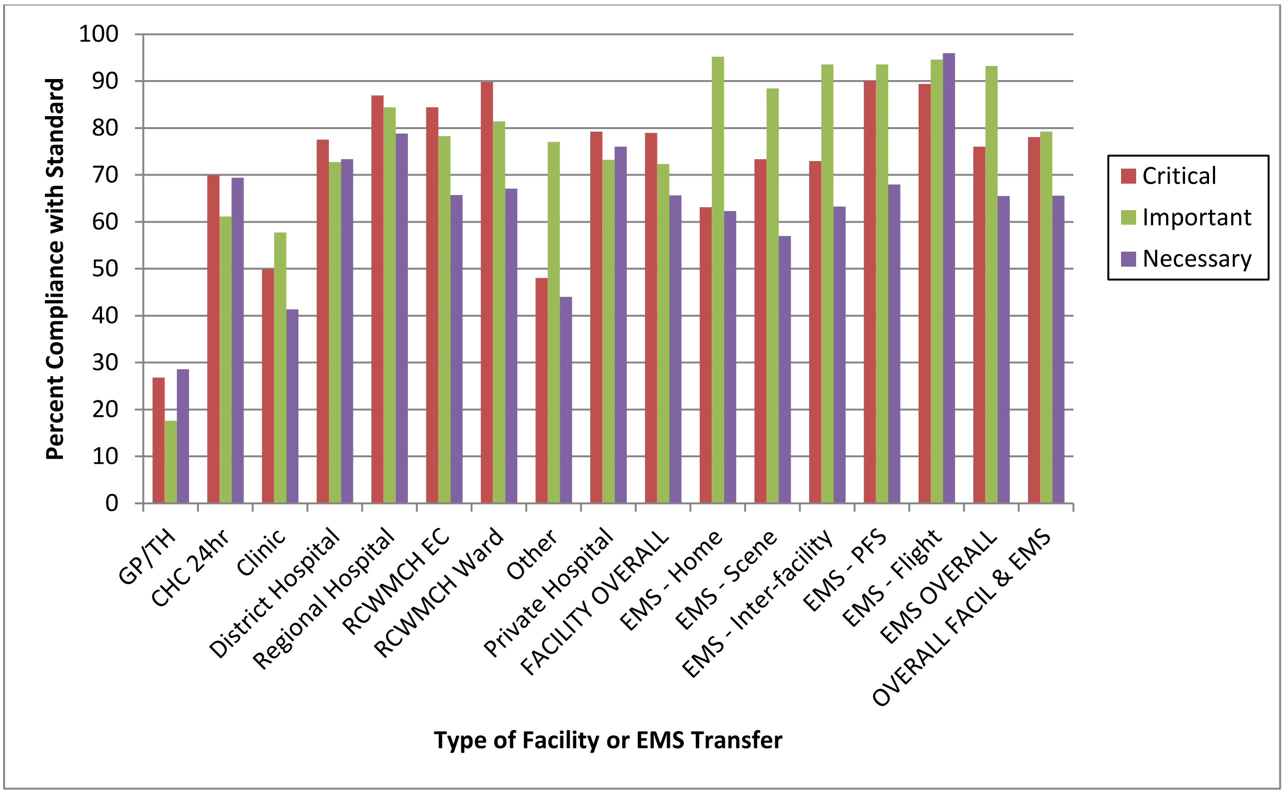


Figure 9-1 Compliance with Standards across facility levels and EMS types

Table 9-4 Compliance with Standards across Standard Diagnosis Groups

	FACILITY				EMS			
Category of Standard	Number of Stds	**% Compliance**			Number of Stds	**% Compliance**		
		Critical	**Important**	**Necessary**		**Critical**	**Important**	**Necessary**
General/Triage	1699	68.6	39.2		2373	14.3	97.6	61.7
Documentation	3891		76.7	76.3	1910		94.7	
Gastro	499	78.3	80.9		197	61.3	58.2	
Gastro - Shocked	262	79.4	60.0		52	52.6	14.3	
Respiratory	794	94.5			313	91.6	80.0	
Respiratory - Advanced Airway Mx	401	97.7	78.5		79	89.5	83.3	90.7
Respiratory - Asthma	103	85.7	89.7	85.7				
Respiratory - Croup	77	92.3	84.0	88.5				
Respiratory - Pneumonia	1093	62.3	85.8	18.0				
Fever/Septic Shock	1124	79.6	76.9	92.3	109	64.2		
Coma/Convulsions	182	81.8	85.2		113	93.3	94.7	
Coma/Convulsions - Coma	81	100.0	88.2		17		100.0	
Coma/Convulsions - Convulsion	88	96.2	93.9	92.3	29		90.9	100.0
Trauma	115	96.4	37.5		99	82.9	75.9	
Trauma - Burns	84	85.3	84.0		18		83.3	
Trauma - Burns - Docs	60			85.0	42			76.2
Trauma - Head Injury	296	91.5	89.6		113	98.1	96.7	
Trauma - Orthopaedics	34		56.7	25.0	7		85.7	
Trauma - Polytrauma	264	91.3	66.2	73.7	76	78.3	93.3	82.6
Referral	1134		72.4	78.1				
ICU Referral	1291	84.9	42.5	11.2				
ALL	13572	79.0	72.4	65.6	5547	76.0	93.2	65.5

Stds standards; gastro gastroenteritis; Mx management; ICU intensive care unit; Docs documentation

9.4 DISCUSSION

The consensus standards reached by this brief and accelerated process, although far from complete or comprehensive represent a meaningful start to the process of developing standards along the lines of international processes. These standards in their present form will primarily serve the current research investigation looking at critically ill and injured children who require intensive care, but will also form the foundation for further development of standards in the province and country as a whole.
The strength of the these standards comes from the consensus of a diversified taskforce with representation from all local role-players involved in paediatric emergency care presents which it was thought would encourage the ratification and recognition of the standards at all levels; and the standards developed are largely attainable with the existing infrastructure, with the exception perhaps of the standards for time and delays, but the targets set are useful if not achievable immediately.

These standards are not ideal, they meet some of the requirements of the research study but will need a good deal of work and expansion before they are a useful tool for quality assessment in the system overall (a process which is already well underway). Some of the weaknesses include: the process was driven by an emergency physician with a primary goal of developing standards for the research project and was thus steered towards the needs of the research project and with an EM bias; the draft standards were primarily based on HIC standards which are not all applicable in the local setting and may have consequently omitted issues which are only pertinent in LMIC, particularly around access to care, and the focus of the standards is on the critically ill child, with less emphasis on the common daily paediatric conditions seen in the primary and secondary health care services.

Finally even though standards should be objective measures of quality, there was a good deal of clinical acumen and judgement required to assess adherence to the standards. Was the airway managed appropriately, may seem a simple question, but requires the insight of whether the nursing sister, EMS crew (BLS or ALS), or junior doctor were able to intubate – if they weren't competent at intubating a 2 week old baby, then without doubt BVM ventilation was more appropriate. Was the HGT checked immediately on arrival? Again this should be a simple binary question – but it relies entirely on if and when it was documented. For this data, a single clinician (PH) primarily assessed all the standards compliance, so there was at least consistency in the application and judgement, but multiple assessors from different levels of experience and insight would highlight the subjectivity of these standards.

A limitation is the validity of the standards of care since they had not been externally validated or gone through a process for validating them as markers of quality – ideally they would have been trialled at different levels and modified to the most feasible, measurable and meaningful indicators.

The taskforce's greatest difficulty was in developing standards which would be applicable to all levels of care – for example management of a head injured patient with difficulty maintaining an airway will differ according to the scope of practice and skills of the treating clinician – who might be an basic/ intermediate life support EMS crew/ paramedic/ nurse/ nursing sister/ medical officer/ paediatrician/ emergency physician or surgeon, as well as the facility and equipment available. The formulated standards are compiled to be as broad as possible, but to include advanced care which may not be applicable to all – so for this example there are standards for basic airway manoeuvres and bag valve mask ventilation as a reasonable option for all, as well as advanced airway management for those with the skills and facilities.

With the above in mind, a specific weakness is perhaps in the EMS standards which are addressed as far as possible within each category, but in many cases are not easy to apply to EMS where the emphasis is on stabilization and rapid appropriate transfer rather than initiating definitive treatment (much of which is out of the scope of practice for non ALS providers who conducted the majority of transfers).

The results from the application of the standards to the PTC data are somewhat difficult to interpret. Firstly collection of these data was an immensely time consuming activity. While it is relatively easy to make a subjective judgement on the quality of care for each step of a child's referral process and even overall, having gained insight to the process from the medical records and the caregiver interview, assessing each objective standard for each step was immensely more difficult (*e.g.* was oxygen given; when and how much of which antibiotic were given). As was even assessing which were applicable (requiring some clinical insight for example was a child who initially presented and was treated as a pneumonia, but subsequently was regarded (or deteriorated to become) a sepsis case) was difficult and required uniform application of the standards for each. The expert panel oversaw the standards assessment and pointed out if they saw a conflict, but they were not able to spend the time in assessing every standard individually.

It was found that deeper analysis and sub-analysis was not clinically meaningful or useful in dealing with most of the data. If there was a specific question to be answered for example what was the compliance with advanced airway management in CHCs then there would be reasonable outcome from this type of sub analysis. What was found to be most useful and meaningful was to use the standards to compare the quality of care at facility levels and EMS types, and in this they are congruent with the findings of the other measures of quality of care (expert panel assessment, and modifiable factor analysis) in showing the increase in quality of care from PHC to specialist hospital care. The analysis and comparison of the different category standards is interesting and important, but difficult to draw too much from as a whole because of the differing numbers of standards and intensity of standards for different categories. For example there were many detailed standards for management of respiratory conditions and advanced airway management, and relatively few for coma/ convulsion management, hence the respiratory standards have likely been more critically assessed, whereas coma/ convulsion standards may give an overly positive impression.

Although detailed standards are necessary and vital for quality improvement, the findings of this study would suggest that standards for each level be individualized, and simplified for assessment purposes, perhaps choosing fewer key sentinel standards for assessment and comparison over time. The positive side of this process, was that it served a role in engaging management and clinical role-players in the research project. Managers became aware of the project, and of the aim to assess consensus standards (which had their input and were not just derived by outside researchers). It was thought that when feedback of the study outcomes is delivered, and when measures are put in place to implement the findings of the study (whether through further research, training or system changes), there would be less resistance and more of a feeling that these were the real and objective findings of a study that they had had some participation in.

CASE STUDY 3

CP was an 8 year old girl. She lived in an apartment building in a low income suburb, with her parents, mother employed, father unemployed, with extended family. Home language Afrikaans, monthly income R2 500 – R 5 000; and they live two km from a 24 hours CHC.

CP accompanied her older brother and sister to a shop across the road from their house at 18h45 one evening. Her sister held her hand all the way, and as they crossed the road, a car had stopped in order for them to do so. However, another vehicle that had been parked, drove out of the bay, overtook the car that had stopped for the kids, and as a result, knocked CP down. The older sister reported that they had seen the car coming but because they panicked she ran in one direction while CP ran in another. The brother ran to the house and got their father, AP to come to the scene. By the time he got there, CP was having a seizure and she was in a lot of pain. One of the passers-by had already called an ambulance. According to the father CP's right side and her right jaw had been injured. Her face was bleeding and her jaw was swollen.

A BLS ambulance arrived 10 minutes later (19h26). Assessed as SATS Triage Yellow, GCS 12/15, injuries: abrasion and laceration to head/ face/ chest. They called for ALS assistance, and with full spinal immobilization began the transfer. They were met by an ALS crew en route to RCWMCH, who reassessed her, concern that she was not responding, gave oxygen and inserted an IV line with a 50ml bolus of Normal Saline.

Arrival at RCWMCH (20h10), CP had a seizure on arrival, given diazepam, immediate intubation (called for assistance from seniors and anaesthetics as difficult airway expected with C-spine immobilization). Intubated with propofol only. Full body digital X-ray (Lodox) performed and no fracture seen. Seen by paediatric surgery (needs imaging abdomen, no obvious injury); neurosurgery (21h30: loaded with IV phenytoin); CT brain performed (showing normal brain and C-spine except un-displaced mandibular fracture); ultrasound of abdomen normal; for PICU admission.

FATHER: AP wasn`t allowed to stay with her at RCWMCH EC, so he couldn`t give an account of events as they transpired while she was there. The only thing he was told was that they had put her on a machine and that they put a tube down her throat to remove the blood. He also remembers overhearing the nurses saying that they almost lost her because her heart stopped beating at some stage and they couldn`t stop her from bleeding. According to him, doctors tried to get CP stable but only managed to do so, sometime after 23:00.

PICU Admission (23h30) for < 24 hours, mild traumatic brain injury, extubated and to the ward the following day, and discharged home on day two with seemingly good recovery.

<u>REVIEW</u>

Global Quality of Care: Good. EMS: Good; RCWMCH EC: Fair

Avoidability of PICU: Not Avoidable

Avoidability of Severity: Not Avoidable

10MAIN DISCUSSION

10.1 OVERVIEW OF KEY FINDINGS

This study evaluated both the nature and the quality of care for critically ill or injured children within the setting of a metropolitan health service, utilizing an approach which is relevant to many other settings globally. The failures of care that were identified contributed to a significant proportion of avoidable deaths and avoidable admissions to the PICU. Overall quality of health care was good in only a small minority (10%) of children, moreover, children who experienced a higher number of major impact MFs or who had poor overall quality of care were more likely to die within one month of admission. The severity of illness at PICU admission was avoidable or potentially avoidable in the majority of cases, and PICU admission itself avoidable in some. The findings demonstrate that the pathway to care from initial health care contact in community settings to PICU has considerable scope for improvement. In addition, given the limited availability of high resource clinical settings such as PICU, improvements in quality of care at “lower” levels of the health care system may have significant benefits in terms of both access to PICU and patient outcomes.

Results of the current study confirm perceived problems within the delivery of critical care, as well as revealing some unforeseen elements such as the prolonged pathway within the tertiary hospital to PICU. In addition to problems with clinical care, there are clearly problems at an organizational and structural level. These are particularly important because they can be addressed at relatively low cost (relative to clinical training). Up to now, however, no data existed on the actual problems faced by critically ill and injured children in accessing care. This study has considerably expanded our understanding of the pathways to care for this group of patients: many of the findings will almost certainly be generalizable to other sick children, as well as to adults.

This approach has been to examine the entire care pathway (from primary care through to PICU admission or death) rather than focussing on individual components. This provides a far better global assessment of quality of care and where avoidable factors occur, at all levels of the health care system, rather than studies in individual institutions or of individual disease presentations. This novel method reveals that for improvements in the quality and safety of care to come about throughout a healthcare system, it will require attention to the entire “pathway to care”, and that even in a relatively well developed system such as exists in the Western Cape, there is substantial potential for improvement with potentially significant reduction in both mortality and morbidity; and improvement in the utilization of expensive services such as PICU.

Although this study, like most other studies of quality of care, has focused almost entirely on the negative aspects of care, it must be stated that there was good care in the health system. The expert review panel, who in retrospect (and relative to the international external reviewer) were somewhat critical of their own health care system, found that there was good care (defined as “health care at an excellent level above average expectations”) in 10% of cases, and another 70% were rated as fair (“health care of an average level expected of the facility/ health care provider”), so actually only 20% of the cases were effectively rated as below expectation, despite the seemingly negative focus of much of the reported data. In addition parent’s perception was overwhelmingly positive about the level of care and treatment received by their children: they claimed to be satisfied with the care they received in 76% of facility interactions (increasing to 92% at RCWMCH EC), and in 73% of EMS transfers.

Overall this health system probably offers the best public sector paediatric critical care on the continent,[338] and likely as good as or better than that offered in other LMIC. Although the study attempted to identify and to celebrate and praise good care, the poorly managed cases did tend to overwhelm the many instances of high quality care. We had undertaken to attempt to identify and feedback good care to individuals and facilities to balance the negative issues, but this was not well done (largely due to the difficulty in contacting individual clinicians, many of whom are shift workers) and something to improve in future studies. Emphasizing this will be one of the crucial points to carry forward as the study outcomes are disseminated to all role-players and the intervention phase begins.

Key issues that were identified as having impact on patients' morbidity and mortality and recurring for each of the major facility levels are summarized in Table 10-1.

Table 10-1 Summary of key issues at frequent sites

SITE	MAJOR ISSUES IDENTIFIED
Clinics	Access to emergency care Assessment/ eyeballing on entry to identify urgent/ emergency cases Assessment and interpretation of severity Resuscitation of shocked children
CHC (24 hour)	Access to emergency care Triage issues and delays Assessment and interpretation of severity Resuscitation and circulatory management for shock Antibiotic delays Referral and transfer issues
EMS	Communication with control and dispatch system Prioritization of calls Response time Inappropriate crew/ vehicle/ equipment for transfer
RCWMCH	Assessment/ identification of severity Delays in critical decisions Antibiotic delays Senior review/ consultation PICU referral delays Inadequate care/ monitoring once referred to PICU

Across the system, the most frequent and important clinical failings were in the areas of assessment, triage, and initial management of the acutely ill child, compounded by delays in decision making and referral. Individual delays at each stage were not always onerous, but the cumulative delays and their impact on small children with extremely time sensitive illness is of great importance. In addition, although perhaps not as well defined because they were not judged or assessed as life threatening issues, there were many other concerns that came to light and are noteworthy, some simple to remedy, others will require system wide changes or longer term educational interventions to remedy. Some of these issues are shown in Table 10-2.

Table 10-2 Key Issues identified across the health system

SITE/ LEVEL	MAJOR ISSUES IDENTIFIED
Facility Level	Communications and advice channels between health care providers Communication and language barriers between caregivers and health care practitioners Analgesia for trauma patients
System level	Poor documentation (elements of missing documentation, and quality of information recorded) EMS familiarity by healthcare practitioners – knowledge about appropriate ems utilization, skill sets and specialized transfer services (such as PFS)
Community Level	EMS access- knowledge about EMS availability and expected response times, and emergency telephone numbers) EMS use for childhood emergencies Awareness of appropriate health facilities for emergencies Education and insight into danger signs particularly in young children and infants and when to seek help
Child Health and Preventative Strategies	Communication between primary healthcare providers Neonatal/ nursery maternal education Identification of high risk children Repeat visits for the same issue Attention to chronic deterioration of children (such as weight loss/ lack of weight gain)

This study assessed the quality of care across a health system, a challenge even for a simple single unit of a facility,[50] and even more so to assess a large number of cases, with varying conditions, and going through different levels of a health system. The study looked at quality of care from multiple angles, assessing every step of the pathway in detail, as well as the entire pathway. We developed standards of care, across the levels of the health system (and found it immensely difficult to apply the same set of standards to different conditions across all the levels of the system). We developed standards for common clinical critical care presentations, and graded these for different clinical implications, as well as defining standards for the entire critical care pathway, and assessed the adherence to these standards. We used an expert panel from various backgrounds to assess quality of care subjectively; and we asked caregivers their opinions and perspectives on the care received at each step. Finally we looked for individual episodes along the care pathway and looked for modifiable factors which likely influenced care and found that the occurrence of major modifiable factors did relate to outcome.

Ideally we would have had an objective measure of the severity of illness or injury of each child at first presentation and along the referral pathway this would answer whether each element of the care was helping the child, and whether the child's condition was deteriorating with time regardless of care. Unfortunately no such tool exists, all we have is a physiological prediction of mortality measured on PICU admission, and the survival and length of stay in PICU and in hospital to assess objective outcome.

As the study grappled with defining and measuring quality of care amongst the bulk of data we collected (outcomes of care, reviewer and caregiver assessment of care, timelines, modifiable factors, and standards), there are some clear overall insights that emerged about the different levels of the healthcare system we assessed. Caregivers had the perception that care was better at higher facility levels (*i.e.* bigger, more specialized facilities), as did reviewers (higher global quality of care) as the levels increased (GP - clinic - CHC - hospital – RCWMCH). There were largely less modifiable factors at higher levels, and adherence to standards clearly improved as the level increased. The only remaining quality measure we looked at was time intervals, which largely deteriorated (*i.e.* lengthened) as the levels increased. This is a remarkable insight. It may be explained in that higher levels of care take longer to deliver, but the reality is that much of the time was spent waiting which suggests inefficient systems as the real cause. This may be amenable to easy interventions.

A retrospective advantage of the review team in this study, (and certainly creating a unique insight) was having the full spectrum of vital sign data available for the entire pathway (see case study example ***Appendix VII,*** Table 0-2 Vitals Signs for Each Step of Pathway), something that the receiving clinician is seldom privy to, except perhaps for the prior step of the pathway. The reviewers were impressed at the information that the trends from this largely available, but isolated, information could provide and this is certainly an avenue for improvement and intervention (even without synchronized electronic records as some HIC might have available).

Documentation was poor across the levels of healthcare, but as for other indices, did improve as the level of care increased. Practitioners in clinics and CHCs seldom documented anything further than their referral letter, while junior staff (especially at higher levels) were apt to write many pages on their management (but not infrequently without a date, time or their own name on the notes). Hospital based nursing staff were largely excellent at documenting times, vitals and nursing care, but independent nursing practitioners in PHC settings wrote abysmally poor notes. Although poor documentation seldom affected care at an individual facility, the cumulative effect across the system when there were usually three or four different health care providers managing a child; reliant on documentation to understand the presentation, disease process and progression, and prior management was surely negative when documentation and referral documentation was bad. Some of the challenges are that documenting the care provided should be useful to the person detailing it, should reduce duplication (*e.g.* not having to rewrite similar notes in a referral letter), and that some of the data need to be available to all the subsequent steps in the process, not just the following one.

10.2 CONTEXTUALIZATION WITH OTHER STUDIES

Comparison with other studies shows remarkable synergy in the main findings, given the apparently vastly different contexts and settings, and methodologies of the comparable outcomes. Lack of triage, inadequate assessment, poor knowledge of treatment guidelines, and insufficient monitoring of sick children were identified as key adverse factors by several other studies looking only at hospital care of children in LMIC.[49,156,339] Studies from critically ill children in HIC, which largely encompass the entire pathway from healthcare presentation, are surprisingly congruent, although more focused, with key issues being delay, lack of recognition (especially around age appropriate vital signs), inadequate management of shock, and inadequate supervision and senior paediatric support.[235-237]

In SA, the ChIP results, although focused on deaths only, define the overall issues clearly as caregiver delay and lack of recognition; delay and inadequate assessment; under assessment of severity; delay in referral; inadequate documentation; and lack of resources (personnel and high care/ ICU facilities).[88] Access to PICU is an international challenge, although with different pressures and issues, but seldom on demand, and a growing field as health systems and critical care in LMIC develop.[6,71,164]

Looking at the four most comparable (although all very different) confidential enquiry studies, how do the PTC overall findings compare? This is probably not a meaningful comparison, since they were all in HIC, and either focused on deaths only, or a single diseases entity, or were in adults. But for completeness, the pertinent and comparable major outcomes are compared.

- CEMACH(2008)[53] showed that 26% of children might have avoided death with better care (compared to 57% in the PTC cohort (10% avoidable and 47% potentially avoidable deaths).
- McQuillan[30] (in adults) had 51% of patients who received inadequate care (up to 40% could have avoided ICU with better care prior); PTC had potentially/ avoidable severity on PICU admission in 74% of children, and up to 24% might have avoided PICU with better care.
- Nadel[235] found suboptimal care in 29% of children; PTC avoidable severity in 74% (they looked at just a single condition (meningococcaemia))
- And lastly, Launay[237] assesses that 71% received suboptimal care (looking at only severe sepsis). (Ninis[236] gives no overall comparable findings)

So even though many of these findings are not directly comparable, there are some surprising congruencies in some elements. But likely all the authors would agree that these overall findings are not particularly meaningful (more of a headline value) – it is the detail of where and what went wrong which the studies sought to answer. The PTC data gives more of an overall system picture, rather than focusing on a single condition or facility (or outcome).

A significant amount of information was collected on each child, including details from each step, and across a range of disease processes, and including information from caregivers. Most other studies of this nature (although none of quite the scale or intensity of this study) have had much smaller sample groups – McQuillan[30] - 100 adults, Nadel[235] 54 children, and Launay[237] had just 21 children, and Ninis[236] who enrolled 143 children (and another 355 controls), indicating perhaps the infrequency of critical illness in HIC settings, and the intensity of the data collection and review process. Ninis[236] compared children who died, to a control group of children who survived their disease ordeal, in order to test the hypothesis that quality of healthcare impacted on outcome (which they were able to do). No association was found between the various measures of quality of care and outcome, and it would have been logistically very difficult to find an age and condition matched control group who did not die or arrive at PICU. The PTC data do raise questions as to whether care received by non-critically ill children (and that of the critically ill who did not get to PICU) was any better or worse, and some form of control group may have answered these questions.

Our data highlight the complexity of the "pathway to care" followed by critically ill children. There are multiple routes through the system, often neither direct nor appropriate, particularly for medical cases, while trauma cases did appear to instigate rapid action and transfer to an appropriate facility. Caregivers had difficulty accessing health care as reflected in delays in seeking help, underutilization of emergency services, and multiple attendances at healthcare facilities prior to the study illness.

In addition to access issues, the time taken from first health services contact through to PICU admission or death was consistently unacceptably long – certainly in comparison to HIC expectations.[261,265,266,282,340,341] Individual facilities and elements may be able to improve delays (and in particular the delays waiting for a PICU bed once accepted), but it is likely that most improvement could be achieved from a review of the overall process and the system.

The health system would appear to have focussed on resource utilization efficiency (ensuring that the medical and other personnel throughout the system are fully utilized) rather than on "flow efficiency" (ensuring that the patient receives the most timeous and effective care throughout the system).[26] This is a difficult concept to fully understand, or even more so to apply to an entire health system made up of relatively fragmented services, each with their own management hierarchy and in some cases separate organizations, none of which treat children as a unique flow which is likely amenable to reorganization and optimization.

A recurrent issue from the review of cases is the delicate balance between continuity of care and continuum of care. The complexity of the pathway routing has been shown, and that patients routinely pass through at least three separate health providers: the biggest group through a PHC facility, then an EMS transfer, RCWMCH EC and then only to PICU. Care is thus potentially fragmented and interrupted along the pathway, unless communications (written and verbal) are optimal, clinicians are aligned in their assessment and resuscitation measures, resources are there to provide the continuous skills and equipment required along the pathway, and ideally there is co-ordinator to oversee the process. Yet the study has identified that each of these elements is suboptimal in this system.

Cape Town has a relatively well developed and resourced EMS system, even by HIC standards, yet this data has demonstrated suboptimal care in many EMS transfers, just as other studies have identified them as a high risk area.[144,342-344] In HIC settings, one of the solutions to provide a high level of continuity of care for identified critically ill children has been the provision of retrieval teams.[141,142,345,346] A specialized paediatric critical care retrieval team is dispatched from the tertiary hospital PICU to stabilize and retrieve a child from the PHC or hospital setting where they were identified, and once stabilized, with intensive care skills and resources, brought back to the tertiary hospital PICU – essentially taking the PICU to the patient. In many HIC settings, this has become the standard of care, with good outcomes,[140-143,347] and is perhaps a definitive solution to some of the convoluted and suboptimal pathways that this cohort of patients experienced.

The CEMACH found that the failure to recognise and manage serious infection was the most frequent avoidable factor in primary care and pointed to the importance of maintaining these skills in the primary care setting.[201] However individual primary care facilities (even in this context with relatively high paediatric morbidity and mortality levels) see relatively few very sick small children (<5 per annum) and improvements in management at primary care facilities may require major educational intervention for relatively small returns. Our data suggest that an educational focus on healthcare workers at secondary and tertiary level institutions would be much more likely to change practice significantly and are compatible with the findings in Kenya.[157,348,349]

The health system has already invested substantially in development and implementation of triage systems,[67,68,151] but these are probably not appropriate in many primary care facilities (especially for GPs and clinics) where most children are being seen for preventive health services and not for the management of acute illness. It may be necessary to rethink screening at largely non-emergency facilities, or how to direct care seekers. Existing triage systems are based predominantly on vital signs, and early data (yet to be fully analysed) from PTC vital sign data might suggest that vital signs, particularly in younger children may be a poor predictor of outcome.

In terms of acute management of sick children, particular diagnoses such as respiratory tract infections were both common and inadequately managed. This does suggest that educational interventions could be focussed on a relatively small group of conditions, rather than a broad range of paediatric diagnoses.

A common theme in primary care, as well as in general ECs is doctors who primarily manage adults were unskilled in the recognition of severity and compensated shock in infants and small children.[236] A body of evidence has been established in high resource settings[36,39,350,351], looking at early warning systems to aid recognition of critically ill children who are deteriorating and require intervention (and PICU admission). Such systems have not been studied extensively in lower resource settings, but given the evidence that severe illness in children is not always apparent at first health care contact, may not be useful in the pre-hospital environment.[351]

10.3 DISCUSSION OF RESEARCH METHODOLOGY

In an ideal study of the pathway to critical care, one would be able to start with any child in the community who develops a life threatening illness or injury. Next best would be to identify all those children at the time of first presentation. This study had to settle for the pragmatic solution of taking children where the critical illness was identified on the basis of death or PICU admission, thus limiting the enrolment to those who made it to PICU, or those who died and presented to a healthcare facility, but missing the group who recovered from their critical illness due to optimal early management without requiring PICU, and those who died in the community without any interaction with the healthcare system.

SA has a still growing but relatively meaningful database and regular reporting from health facilities around the country on childhood deaths in the form of ChIP.[88,312] There are fundamental differences between this study and ChIP, primarily that ChIP only collects deaths from healthcare facilities. ChIP only includes those who voluntarily subscribe to the system (and even within RCWMCH not all wards and departments contribute to ChIP data collection), thus selecting those already implementing quality improvement. The ChIP data are collected purely from record review at the final health facility (hopefully with a referral letter giving some insight into prior management), relying on clinicians taking a full history, and documenting their findings and management thoroughly, and with no further insights gained from the family/ caregiver into the actual development of the illness and health seeking efforts, or even prior health interactions. So valuable as the ChIP data are, and it has proven feasible to collect and collate this data countrywide,[223,230] they do not give the depth that this study and methodology is able to.

This research shows that a longitudinal retrospective review of care across levels of a health system is a useful approach and can be conducted, with additional key information from interview with caregivers/ patients. This presents a novel research approach, and although the logistics of this study were daunting and it may not be directly replicable in other settings, the principles are easy to apply and some elements could actually be embedded into routine care providing ongoing audit of clinical care, referral pathways and patient perception/ perspective.

10.3.1 Sample

The study enrolled a smaller sample of children than we anticipated, and the proportion of children with good clinical care was 10%, which was lower than we originally expected. Given our recruitment of 282 children this provided a precision on this estimate of 4% (95% CI 7%-14%) consistent with what was felt to be clinically meaningful during study design. We were only able to collect data on alternate weeks – the intensive, time consuming nature of the interview process, summarizing and data capturing elements of the interview process, and identifying and collecting medical records from distant facilities and then entering them into the database meant that a backlog would have developed had we enrolled continuously and not allowed rapid, hot pursuit of the data collection.

The more stringent inclusion criteria (compared to the pilot study) excluded elective cases (137 (37%) of excluded PICU cases), chronic conditions (114 (31%), and neonates admitted directly from nursery (42 (11%), thus reducing the enrolled cases to 282 (from the planned 400-500 cases based on the pilot study and admission figures). These excluded patients do have a pathway but of a different nature; for those in hospital for a substantial period, the issues and delays are different to the acute admissions, and the pathway for neonates who have not yet been discharged home after delivery is another subject.

Child Death Sampling

In order to offset the critically ill children who made it through the system to PICU, we in effect oversampled deaths by including children who died prior to PICU admission and at a sample of other health care facilities in the study. We were not able to include those who died outside of the healthcare system due to logistical constraints, although in some cases it was difficult to judge whether a child had died prior to the presentation. We went with the decision of the healthcare practitioner as to whether they elected to start resuscitation as to whether to include these cases when in doubt (although in some cases this assessment was made by a junior doctor and was perhaps a futile attempt).

It was not feasible to collect a sample of *all* children who died within the region (particularly those who died at home) due to the slow and laborious nature of the death registration process and the poor quality of these records[85], hence there may be a survival bias, but our additional sampling of children who died outside of the referral hospital provided information on wider aspects of the system.

10.3.2 Collection Issues

The recruitment and enrolment process was effective in identifying only emergency cases – but in effect there were many cases screened laboriously and requiring some clinical insight to apply the inclusion and exclusion criteria. Many were cases with a complex hospital referral process, as well as those with long term health issues where it was not always clear whether an admission (or death) was expected or planned. There would be value in assessing the deaths of children prior to arrival at a facility, but this was beyond the scope of this study and the data collection methods (which relied on documentation).

A number of caregivers, 62 cases (18% of those eligible) did not consent to participate, understandable at the time of their child's illness or death. A third (21 of the 62) were contacted following the death of their child, while others may have died after PICU admission (and in some cases before the approach of the recruitment team). We were relieved that our enrolment process was effective, and believe this was an acceptable refusal rate given the circumstances (we were careful to avoid any form of coercion to caregivers to participate), and there did not seem to be any specific pattern or group of caregivers who refused consent. In fact 77% of caregivers did not find the interview stressful and most (89%) were prepared to participate again which we see as a positive indication that this research is acceptable. Missing data were seldom an issue due to the prompt data acquisition and the rigorous data collection process. There were less than ten interviews that were incomplete to some extent (parents called away, inability to communicate adequately, or caregivers who were not present at the time of illness/ injury), but it was judged that there was sufficient information to include the cases. Documentation was unobtainable in very few instances due to the co-operation of the various health facilities and practitioners and in these few cases adequate assessment of the pathway was made from other information.

It was thought that a key issue in obtaining high quality data would be promptness to ensure facility and EMS documents were easily obtainable, that key clinicians could be contacted within a reasonable time period for further information, and that caregivers were interviewed as soon as reasonably possible after the episode. This was certainly true for tracking records and caregivers, but less so for contacting clinicians for further information. Early attempts at consolidating information by discussing with clinicians involved were not especially enlightening – often there was little the clinician could add retrospectively to what had been gleaned from the available information so this was perhaps not as useful or important as originally thought.

Forging relationships with key personnel at each facility were crucial to successful record collection due to the sometimes chaotic environments and somewhat erratic manual filing systems.

10.3.3 Interview Issues

The recruitment and consent process was effective, with high enrolment rates. Parents were more difficult to contact and less likely to agree to participate when their child had died. The personality and strategy of the interviewers (all experienced in conducting interviews, but with variable healthcare backgrounds so they lacked insight into some aspects but this was seldom problematic) was key. There may have been some differences in the enrolment between interviewers, although hard to separate the different language and population group differences from any interviewer bias. Interviewers (and caregivers to some extent) found the interactions with parents whose child had died particularly stressful, often with an expectation from caregivers of further information about the death from interviewers, and recall of the often traumatic events around the death. Debriefing and trauma counselling were offered to interviewers following several instances and cases which left interviewers stressed and traumatized (particularly those with poor care and bad outcomes, cases where the caregivers were not acknowledged and communication was poor, and caregivers who expected answers from the interviewers on the outcomes and care issues for their child). These interviews were the minority, and most were well received, with most caregivers reporting them to be stress free and happy to undergo further interviews.

10.3.4 Caregiver insight and perceptions

Interview data provided a wealth of information not otherwise documented, particularly around access to care, time delays along the pathway, and various other undocumented issues as well as the perceptions and satisfaction of the caregivers with the care delivered. This was a unique element not included in other longitudinal studies which provided rich data which would never have been captured from documentation alone (even in a system with more thorough and inclusive documentation systems). There is a great deal of information still to be gained from the qualitative analysis of this material, still being analysed and publications drafted. Much of the analysis to date (and the focus of the interview material since the caregivers focus tended to be on the earlier elements of the pathway) is on access to care and the early barriers prior to being seen by a clinician and identified as critically ill.
The researchers went into the study with a clear ethos to avoid levelling "blame" at caregivers for the presentation (or delayed presentation) with their children, and in many cases having the perspective of the parent and understanding the difficulties of accessing good care became apparent.

10.3.5 Review Process

Outcome Blinding The reviewers were not blinded to the final outcomes for each case, in fact by the time they reviewed each case the outcome of the PICU admission was almost always available and visible, introducing an observer bias when assessing quality/ modifiable factor categories. It is possible (and even likely) that this knowledge affected their assessment of the quality of care, with harsher judgements and more modifiable factors linked to these cases.[352] To reduce this bias, there were clear, written definitions of categories, multiple reviews and consensus building. Although blinding to outcome could (and arguably should) have been made part of the review process, in the light of the many poorly managed cases who did survive it is unlikely that it had a great impact. In fact the regression analysis was unable to link outcome to any reviewer assessment other than the number of major modifiable factors, which would strengthen this argument.

Consensus

The multidisciplinary review team proved powerful in covering all aspects of the system, with specific insights into the context and expectations for each level of care, as well as (retrospective) insights into the pathophysiology and outcome for each case. Agreement between reviewers was largely moderate (unsurprising given the very different background specialities of the reviewers and the obvious focus of each on their own speciality areas) but rapidly resolved at consensus meetings. Consensus decisions may have been somewhat swayed towards the PICU paediatrician who had greater insight into the pathophysiology as well as internal insights on some of the individual cases and outcomes.

Most of the reviewer disagreement (prior to consensus meetings) and consequently the predominant discussions at consensus meetings was around whether the severity of illness at PICU admission was avoidable or potentially avoidable. In retrospect it was often easy to consider how care could have been improved, and this had to be balanced with what the reasonable, expected care for the context should and could have been. Consensus decisions were more likely to err towards *potentially avoidable* once a suggestion from a reviewer had been introduced.

One of the challenges was that if only one of the steps in a referral pathway goes wrong then the entire pathway was classified as being poor (in fact if each step contained all the correct actions, but just took too long, one could classify it as poor). It was difficult to be consistent with this across cases and contexts, particularly as the study progressed and each reviewer developed preconceptions and bias – although moderated by the group consensus discussions.

Agreement

Agreement between the different internal reviewers was initially moderate, although according to how one interprets the kappa scoring[353], this may actually be a reasonable indicator of agreement for such a complex, subjective assessment. Given the different backgrounds of the expert panel, and the relative paucity of their knowledge of one another's fields given their specializations, the disagreements seem minor, and 100% were resolved without a lot of discussion at consensus meetings which provided the opportunity to address any conflicting viewpoints.

10.3.6 External reviewer

There was a lower level of agreement between the internal and external reviewers, with the exception of avoidability of PICU. The external reviewer, based in London, was chosen because of his expertise and experience in global paediatric emergency care and had worked in several LMIC settings including in SA, although not in Cape Town. Although he was part of the initial reviewer training, and was able to communicate with all team members, he was not privy to consensus meetings and discussions with only summarized specific feedback from theses discussion, and had incomplete contextual insight, and tended to be more generous in quality of care assessment. This was perhaps to be expected when he was working in a HIC system and viewed the research cases in the context of LMIC healthcare more generally, and perhaps not that of the Cape Town context.

10.3.7 Starting Point

An issue confounding the clear cut identification of critical illness is that while a critical injury occurs at a particular point, critical illness may have a gradual onset, and may in fact have a complex progression over several days (e.g. the child with adenoviral pneumonia that gets worse despite appropriate therapy at every point). So defining when the pathway to care began was not always easy. For the majority of children there seemed to be an acute deterioration within hours or a day which prompted accessing healthcare, and for these it was largely clear. But some children with an acute on chronic deterioration defied any definition of time/ place or presenting problem to link their healthcare episodes – although they were (in retrospect) clearly linked – the repeated example from the data being the child with TB meningitis who deteriorated over weeks, with repeated healthcare presentations (for weight loss, loss of appetite, malaise *etc.*) without a diagnosis and sent home, until an acute deterioration such as confusion and focal signs made the diagnosis clearer and precipitated urgent referral and management. In such cases we made a consensus decision on when a meaningful acute pathway to care started, and we were able to collect information on the overall performance of the healthcare system, rather than simply the components thereof.

10.3.8 System Issues

To address the boundaries of when an acute episode began, versus an ongoing ailment, an assessment was added as to whether there was likely a health system issue at stake prior to the acute episode which could and should have been managed to prevent the episode which helped to clarify and separate the longer term issues from the acute health care management issues. Given that health care delivery involves multiple interwoven issues, it is likely that there will be difficult boundaries in many areas.

10.3.9 Environmental Scan/ Underlying Issues

The study took no cognisance of other key factors at play during each healthcare episode – particularly the staffing, clinical load and capacity of any facility. Further research will be necessary to explore these factors which are clearly important. The data had however provided clear insights as to where to target these studies – the facilities seeing a high frequency of critical children, and in the areas identified – for example the ECs of CHCs, and the RCWMCH EC.

10.3.10 Strengths of the study

The challenge of a research project such as this which looks across a health system through many levels is to balance the logistics and reality of conducting the research with the level of detail required. This balance has implications on the resources required to conduct the research in order to show that the study was reproducible, particularly in other settings where this type of research has the potential to impact on many other health system (for example adult critical care) and other countries throughout the world.

Caregiver Interview

The inclusion of a semi-structured interview as part of the assessment and audit of healthcare was a unique element of this study. Other studies of this nature may have gained some, missing information from caregivers, but not to the depth and rigour obtained. Although there was an initial concern about enrolment, and stress on bereaved and traumatized parents, this was not the case and the interview process was well received, and logistically not that difficult to conduct, especially with the caregivers of children in PICU who were readily available for interview. They provided unique insights into the barriers they experienced, giving the reviewers and the study as a whole a new perspective to the difficulties of navigating your sick child into and through the health system.

Critical Care *vs* Deaths alone

Confidential enquiry in HIC is becoming more difficult as there are fewer deaths to investigate, and consequently issues of confidentiality, as well as inadequate numbers to assess patterns. However in most LMIC there are many childhood deaths, but largely inadequate resources to perform an in depth audit and analysis of these cases. This study has shown the value of examining critical care as well as deceased children, and this allows focus on the high risk population. This methodology may be pertinent to HIC settings where although there are few deaths, there are relatively higher numbers of children with critical illness to audit, with potentially wider implications.

The results proved difficult to link to outcome, although the initial strategy may have been to stratify cases into those with good care and outcome versus those with poor care/ outcome, and to find common issues within each group, this was not the case, partly because the system is far from perfect and cases with faultless care and outcomes were few, and in picking only the critically ill and dying patients the focus was already on the group with severe disease and difficult management options.

Overall insight

This study with detailed review of each step of the process has provided unique and crucial insights to understand how the system overall may be improved. It has been able to assess the relative values of each element in various ways, including the duration of each step and assess where and how best to target future interventions. The study has tackled measuring and assessing quality of care in different ways, but with largely parallel outcomes, although each providing different insights and angles for improvement.

Evidence for Policy Makers and Managers

Although many of the findings of the study are no surprise, the study gives real participatory evidence to take back to role-players at every level. Feedback to individual elements from the study, with the insight that their own patients and data contributed to the study is an immensely powerful tool. Already there has been dissemination of many of the findings of the study to various role-players, with selected results to show specific assessment and issues (good and bad) at specific levels (and sometimes at specific facilities) which has been positively received, and accepted in a far more constructive light than a more centrally conducted study from a highpoint suggesting care was poor across the system because of the findings at the referral facility for instance.

Mapping out the complexity of the pathways was also a useful exercise, anecdotally known, but not detailed to this level. This will be a useful tool in demonstrating the complexity of the systems, and the potential ramifications of system changes and improvements across the referral system.

Generalizability

Although health care in Cape Town is different to that provided in many parts of the country or in the sub-Saharan region, these results are mostly transferable to these settings: the same problems will face providers of critical care for children in other large metropolitan settings.[81,354] In addition, many of our patients have a rural component to their pathway and these finding are transferable. The methodology of this study is directly repeatable in other settings, to provide an in-depth analysis of local problems with critical care.

Critical care failures addressed by this research will be common to most healthcare systems in similar settings.[355] Moreover, the methods to assess these, intervene, and monitor progress of quality of care are going to be increasingly important for health care systems and policy makers in the many similar settings in LMICs.[156,348,349]

10.4 CHALLENGES AND INSIGHTS FROM THE DATA COLLECTION AND ANALYSIS PROCESS

The methodology of the study, the results and the strengths and weaknesses of the study have been described, rationalized, and discussed in detail. In order to take the insights of this process forward, it is necessary to assess which elements of the data collection and review process were most valuable and to balance this with the resources and time necessary. This project was a relatively resource heavy endeavour, only made possible by a substantial research grant, and the inputs from a team of international expert collaborators. Ideally, the study would be repeatable in the same setting to assess improvements over time and following specific interventions, and repeatable elsewhere – such as in a HIC setting, in a rural setting, and in less resourced LMIC urban areas to allow comparison of the findings.

Although the study seemed resource heavy – the cost of the project was in the region of three million Rands, one could argue that in the context of just Cape Town's critical care burden (the RCWMCH PICU annual budget is about 70 million Rands (personal communication A. Argent, 2015)) and the system wide cost of critical care far more, this may be good value. Repeating the study, with the infrastructure and proven methods in place would be less expensive, so if this methodology can provide profound insights that drive improvement, it could be shown to be a worthwhile resource.

So which elements were relatively high value and could be repeated or even built into health systems for ongoing quality assessment? Table 10-3 Assessment of the value and efficiency of each element of the PTC study in Table 10-3 lists the main elements of the study, and gives an indication of the cost and relative value of each element to the study outcomes, the time spent on each element, the quality (*i.e.* the completeness and congruency with other data) of each, and whether the element would be essential in subsequent studies of this nature. Each element is further discussed below with specific reference to how they might be improved in subsequent studies utilizing this or similar methodologies.

10.4.1 Enrolment, database and data collection

The online database was indispensable for the study in the present form, allowing large volumes of digital data to be stored, accessed from anywhere, and facilitated blinded online review and some analysis. A smaller, more focused study could perhaps be undertaken without this online component (paper records), or a simpler database. In theory this database has been built now and the same database could be modified for use elsewhere. Problems with this are it is dependent on fast internet connections, and would need an information specialist familiar with the original database to drive it.

Table 10-3 Assessment of the value and efficiency of each element of the PTC study

ELEMENT	Expense	Value	Time	Quality	Dispensable?	Comment
Ethics and approvals	-	+	++		no	Unavoidable unless part of ongoing continuous quality improvement
Online Database	+++	++	+++	+++	possibly	Ongoing use of same database perhaps Modification to streamline Less reliance of online internet
Caregiver interview	+	+++	+	++++	no	Key element Refine semi-structured interview to focus on other areas *e.g.* health seeking behaviours and access
Interview summary & data entry	+	+++	++	++	no	Gave useful rapid assessment and summary Ideal for mixed methods analysis
Transcription & translation	+++	+	++++	++	yes	Qualitative analysis sample size could be focused and smaller
Screening & Enrolment	-	++	+	++	no	Worked well for PICU with waiting parents, could extend other similar contexts with waiting parents
Facility Data Collection	++	++	++	+	not in present system	Digitization of records ideal Documentation on proforma that enforce/ encourage more and higher quality documentation
Facility Data entry	+	+/-	++	++	partially	Over- collection, needs focus Digital records
EMS Data collection	-	++	-	+++	no	Easy, likely digitized soon Central record storage ideal
EMS Data entry	+	+	+	++		Digital records will streamline
Death Identification	+	++	+	+	maybe	Central database/ registry Need system wide identification of deaths, including prior to healthcare
Death Screening & Enrolment	+	+	++	+	yes	ChIP like system may be superior Include as part of counselling services?
Death Interview	+	++	+++	++	partial	Sampling to reduce number, perhaps less informative on health issues Unexpectedly good enrolment
Standards Development	-	++	+	+/-	maybe	Simplified, level appropriate, more objective

ELEMENT	Expense	Value	Time	Quality	Dispensable?	Comment
Standards Assessment	++	-	+++	+/-	modify	Need key objective standards that can be assessed by anyone
Modifiable Development	-	+	-	++	no	Rapid, functional, relates to international and ChIP data
Modifiable Assessment	+	++	++	+++	no	Useful, could be focused
Clinical Review Process	+	++	++	+++	no	Needed clinical insight. Better collation might streamline
Expert Review Assessment	++	+++	+++	+++	no	Key process. Consider how to streamline as time and expense limiting. Blind to outcome.
Expert Review Consensus	+	+++	++	++	no	Questionable value as conducted. Need individual outside of system, but with full contextual insight and experience
External Reviewer	+	+	++	+	+/-	Uncertain objectives, needed better contextual insight
Analysis	+	+++	+++	++	no	Future analysis will be more focused and goal directed with the insights gained

Interview Process

The interview process was easy to set up (facilitated by the experienced chief interviewer KJ), the main expense was the interviewers' salaries, and it was well received by caregivers (without apparent distress since many were prepared to undergo further interview). Most caregivers were in the PICU area or waiting room supporting their child, so they were not inconvenienced or difficult to contact. The interview provided insights which could not have been gained elsewhere (timelines, chain of events, pathway, perceptions) as well as further insights (health seeking behaviour, access to care) which could have been further assessed. Interviewers summarized the interview and entered key demographic type data into a database after the interview. This provided the primary information for review as they highlighted pertinent points and extracted key data themselves. This was done rapidly soon after the interview, whereas the transcription and translation process was extremely time consuming: even working full time over 14 months (including conducting the interviews and data entry), the three interviewers only completed just under half the transcriptions and translations of the interviews they conducted. Once the qualitative analysis was underway, it was rapidly assessed that a far smaller sample was required (30 transcripts) to reach thematic saturation and this element should not be repeated without careful consideration and selection.

Screening and enrolment

Two research nursing sisters performed the screening process, and once established involved a rapid daily walk around the PICU and review of the admission records. A clerk probably could have conducted some elements of this process, streamlining it, but there was clinical insight required. Enrolling and consenting caregivers was done in a two stage process: initial introduction of the study by the screening nurse, followed by a formal consent process by the interviewer immediately prior to the interview. This worked well, and was an unintimidating way of enrolling caregivers without coercion.

Identification of the children who died was straightforward at RCWMCH where there was a single register kept by the reception clerks, although screening was not always straightforward – actual records and EC registers had to be traced and checked against inclusion/ exclusion criteria. For facilities outside of RCWMCH, the process was difficult and imperfect and relied on multiple sources at each facility. Future studies would need to carefully consider alternate mechanisms – perhaps through central death registries, or even the state mortuary, as well as a better mechanism of separating in facility deaths from deaths prior to facilities. Ideally this death record collection and audit could be best performed by the facility clinicians – the pathways are usually simple and straightforward and there is no great complexity to the assessment. Perhaps ChIP or a modified ChIP like system working at smaller facilities (such as CHCs) could perform this process more efficiently.

Sampling and duration

The study enrolled children alternate weeks for a year. In the current form, this was the maximum enrolment rate that the team (seven full time research team and three review panel) could manage. So questions need to be asked as to whether it was necessary to sample year round given that the seasonal spread of diagnoses and the review seemed to be more or less constant over the year, would there be any reason to collect year round again? And would it be necessary to sample as many children? The power calculations to determine the sample were worked around what were believed to be the best indicators, the number of critical care failures, *i.e.* the number of children experiencing major modifiable factors. But in fact the sample was far higher than most other similar studies, and in all likelihood would have reached the same conclusions with half the cases. Preliminary data analysis halfway through the study period showed almost identical outcomes, suggesting this is true. Power calculations would have to be reconsidered perhaps in the light of the findings and perhaps using other indices given the high "clinical failure" rate. Certainly a shorter, perhaps more intensive study (enrolling every week rather than alternate weeks) might be more viable and cost effective, with similar results. An alternative strategy might be a lower sampling rate, conducted year round (which would include any seasonal variations), but conducted by a small, part time staff component.

Record Collection and data entry

Collection of medical records was performed by a data clerk driving out to each identified facility around the metropol on a daily basis, tracking down paper records in facilities, digitizing (photographing) on site, and then uploading these to the database. Once the clerk had established relationships this process was fairly straightforward, although time consuming (and expensive in terms of the vehicle costs). Identifying the actual facilities visited by a child was not always straightforward – caregivers and records were not always clear on the facilities or dates and times. Once in the correct facility, tracking down the records required some persistence, following up too soon after a child's consultation/ admission would mean the paper records were not yet filed and still in the EC/ consulting areas of a facility, yet when left too long they were apt to disappear (misfiled, taken elsewhere, *etc.*). Records at the tertiary hospital were usually at the bedside in PICU or easily accessible so this was only an issue for prior facilities. Until digital records are a reality, research of this type will be dependent on paper records and collection from each facility. Referral letters were often missing from destination hospital records, and seldom gave a complete picture of the child's condition or management. Identifying study participants prospectively and demanding copies of notes sent with referrals would perhaps be an option, but would likely sensitize staff to a study case and change their management.

Once facility and EMS records were collected, key data were identified and entered into the database. In retrospect, far too much information was entered and this process could be streamlined. Data that were actually used in the analysis were timelines, facility names and levels and vital signs. Much of the rest of the entered data was unused to date (and could be entered at a later date from digitized records should the need arise). Entering less data could in theory have allowed just a single research nursing sister to perform the task. In addition there were no standardized medical records – many were handwritten on blank paper, making the task of seeking out information much more difficult than it could have been if written on a standardized clinical record sheet (as EMS do).

EMS data was much easier to collect. In most cases a single page patient report form (PRF) held all the information, in a standard format, making it easy to identify each element. These were often in the receiving hospitals notes, but even when missing, copies were centrally held and easily obtained (faxed on request). In the near future such records are likely to be digitized which would make the process seamless and invite much data accessibility and availability (real time for clinicians, as well as retrospectively for quality assurance, research and analysis).

10.4.2 Review process and analysis

Once province wide standards are in place and accepted, the need for developing standards *ab initio* will shrink. In their current form assessment of standards compliance across all health care levels was cumbersome, time consuming and subjective. Some of the data produced was useful, but probably not worth the detail and effort. Selection of a few key and clearly measurable standards, appropriate to each level and probably across different patient presentations (to avoid the extra layer of subjectivity as to which standards are applicable) would be easier, less time consuming and give better, more repeatable outcomes. This study added yet another assessment to the standards assessing whether each standard was documented or not which was time consuming to capture and not meaningful. Furthermore rigorous piloting and refining of the standards would add value and validity.

The modifiable factor list was rapidly assimilated from various sources. The assessment was time consuming, but not as much so as the standards (the modifiable assessment being gleaned from more of an overall impression of each step, rather than having to assess individual timelines and clinical aspects as the standards required). The outcomes of the modifiable factor analysis seemed to be meaningful, were comparable to other studies and would be repeatable. And could be focused more on specific aspects if necessary – for example the frequent "resuscitation inadequate" could be subdivided into resuscitation airway/ resuscitation breathing/ resuscitation circulation *etc.* to give more detail. The grading system seemed to work although the near miss category was not often ascertained from documentation.

Review Panel

The clinical fellow assimilated all the data records and interview summaries, and made the decision whether there were adequate data for review. He then developed a summary and timeline, and reviewed each element of the case including the allocation of standards and modifiable factors. This was a very time consuming process, each case could take several hours (many hours for complex cases with multiple steps) to complete, so this was a full time role. With reduction in the standards assessment, and perhaps more standardized records to make assessing them faster, this process could have been faster. It was found to be necessary to have a senior doctor, with broad and local contextual insights to conduct this process. This is however an expensive resource and consideration could be given to other personnel although there would be less clinical information and assimilation and consequently longer review required by panellists.

The expert panel blinded review process was designed so that the panel could review cases independently online, anywhere and anytime that it suited them. The database was effective in the review, if reliant on high speed internet which wasn't always available; the main problem being the mass of information the reviewers had to go through on each case. Reviewers all read the interview summary and the clinical review summary, and then looked at the various medical records, likely spending more time on those from their discipline. Even some months down the process, the reviews took time and a backlog began to develop. At the end of the data collection phase, the review panel was several months behind and the catch up was facilitated by two consecutive off site days of independent review with consensus discussion after every 10 cases completed. Although the expert panel review was integral to the quality assessment, it was extremely time consuming for busy professionals, and future studies would have to weight this against the outcomes.

Given that there was fairly good consensus between the reviewers, perhaps a single reviewer with insights across the system would reach similar conclusions? And perhaps a panel could consist of more junior consultants, and not necessarily such senior heads of department figures with extreme time constraints (but clear system insights). The reviewers variably made free text comments which may have slowed them somewhat but the various comments reached thematic saturation rapidly so were not all necessary. On the positive side, all the reviewers found taking part in the review process to be an insightful process, giving new understanding (especially from the perspective of the patient/ caregiver), perceptions and vision for improvements in their specialities and system wide, as well as gaining insights to the issues for other specialities and components.

Consideration might be given to some or all reviewers being peer reviewers from outside the healthcare system, but within the context of the country/ health setting. Although the external reviewer in this study was outside of the country and continent and possibly not fully informed to the context of the healthcare system and may have been too generous in assessing quality of care, perhaps the internal reviewers were over critical of their own system and an outside reviewer could be more objective.

An important point to strengthen future studies would be blinding reviewers to outcomes. Although it would leave cases somewhat open ended (reviewers could get the outcome data once they have entered their review), this could simply alleviate the elements of outcome bias which likely played a role in this study.

Consensus meetings were useful on several levels: reviewers were able to agree on grey zones and how to judge them early on, and then maintain consistency, various viewpoints were aired and debated, and commentary added on cases. The external reviewer's role was not as clear. He provided expert comment on issues and suggestions for improvement, but it was in retrospect unlikely that he would have the local contextual insight, or assess the expected standard of care from a distance. While a neutral expert seemed a rational approach, the value and expectations of this role would need better defining in future.

Data analysis

The analysis of the data once collected took an inordinate amount of time, despite an online database which facilitated a good deal of the analysis, and planning the analysis in advance. Some elements were relatively simple – the objective outcomes, reviewer assessments, demographics and timelines were initially straightforward. Describing and analysing the complicated pathways was more difficult, but it was the analysis of modifiable factors and standards which was most taxing. There were a variable number of steps for each case, and a variable number of modifiable factors and standards applicable to each step, making the data difficult to deal with. Simplifying these indicators, as well as for the standards certainly trying to keep a small number consistently applied for each level would be a better approach.

10.4.3 Conclusion – the viable, but meaningful methodology

To conclude, there are certainly key elements that are indispensable to this process: caregiver interview, medical records collection, clinical assimilation and panel review. Elements that might be excluded without impacting on the overall results would be the deaths prior to PICU since they represent such different issues, external review, excess data collection and entry, and undirected transcription and translation of interviews. Standards, if used at all would need to be streamlined and much more rigorous and simple to assess. Furthermore, there may be value in a much more targeted modified PTC methodology, for instance looking at just referrals from a specific geographical area, or those seen at a single facility or type of facility to assess interventions or system changes. The major expenses of the study once underway, were staff salaries for the team of seven full time researchers. Future studies would have to consider the value of each employee, and whether a lower paid individual could achieve the same outcome, or a simpler process would allow fewer researchers and less time spent on the various components.

If money and time were no object, the existing process could well be used again, but with better standards, reviewer blinding to outcome, and less emphasis on the hot pursuit elements (it was important to conduct interviews and to get medical records soon after the events, but the review process could easily have been conducted much later), and either a more intense data collection over a shorter period (a month or two), or a less intensive sampling over a longer period would likely give similar results, yet require less research resources.

11 RECOMMENDATIONS

On first impression, the title of this thesis, “Developing a… pathway…”, may seem misleading, and lead the reader to think that this reports on research around implemented changes to improve the paediatric critical care pathway. At this stage it should be clear to the reader that defining the problems were much more complex than any one simple identification/ intervention/ monitoring cycle might suggest. But giving strong evidence for what the problems are and where they are, through a rigorous and respected technique with system wide buy in to the findings, we hope sets a good deal of the groundwork towards improvement. The data have allowed identification of a large numbers of issues in the system, some amenable to system wide interventions, others focused interventions at specific entities and levels of care. Some will require major system wide changes, others could be implemented reasonably easily through management decision or policy changes. And yet others may take decades to improve (for example input on undergraduate medical curriculums and training programs and awaiting the benefit of these clinicians in the system), while others are amenable to short course learning and on the job skills improvement.

The data highlight priorities for quality improvement, but the complexity of the pathways to definitive care has made it clear that any interventions would have to be extremely carefully mapped out both in terms of scope and assessment of effect so as to avoid further adverse outcomes. The prospect of any reduction in number or length of PICU admissions provides the potential for substantial improvement in utilization of scarce resources (and possibly financial savings) in addition to improved patient outcome.

Since the completion of the study, there has been widespread feedback of the findings, initially to senior management with key stakeholders at both City Health and the Provincial Department of Health, and UCT Faculty of Health Sciences. Managers embraced and accepted the findings with enthusiasm, and gave their support wholeheartedly to the outcomes, but may need input and guidance on how and where to intervene to improve the critical care pathway. Feedback continued (and is ongoing) across all levels, to the City Health executives, to paediatric and emergency forums, to individual facilities (particularly the high frequency PTC facilities) and across national and international academic forums (***Appendix IV***), with interest and acclaim from many parties.

With managerial support in place, we are in a position to suggest and effect changes at several levels of the health system. The exact nature of these changes will have to be discussed and realised, ideally with monitoring of the impact of individual levels, the system as a whole, and on non-critical patients.

Again it must be emphasized through this process that care is not universally poor, some aspects were very good, and even within the community settings some care sites were better than others, as some levels were better than others. There is no doubt that much of the system is working, but just not at optimal efficiency. Suggestions for recommendations are described below, classified by the area and type of intervention, not necessarily by priority, nor by the expected difficulty or length of the interventions.

11.1 System Wide Interventions

11.1.1 Access to Care

Although not a primary focus of this study, it was unavoidable to gather from the data we collected, particularly from the caregiver interviews, just how hard it was for many parents to access emergency care. Desperately poor parents, seeing their children only after working hours when most facilities are closed, with limited transport, and sometimes not speaking the language of health care providers, are a real challenge to tackle and more socio-economic in nature. But parents were largely ignorant of the EMS service and its efficiency. Community wide education of how and when to call an ambulance, and systems for ambulances to safely identify and access callers in informal areas may be easily accomplished. Primary Health Care facilities in high density areas could also consider extended opening hours to suit working parents.

Once a caregiver had arrived at an open health facility with emergency care, there were often still barriers. Gatekeepers and security guards, although often helpful and knowledgeable, could be a barrier to get through with a sick child, and then the routing to the appropriate emergency area inside the facility was not always obvious. Once in a facility, inevitably staff would require a folder to be found or opened before a child could be seen, and then there may or may not have been a triage process, often daunting and unexplained to newcomers. All these issues are amenable to simple signage, patient friendly staff, and more effective queue marshals or gatekeepers – none of which are particularly resource intensive. In Malawi,[150] a simple but effective reorganization of a busy emergency area to triage and direct people to specific areas as they enter the unit resulted in dramatic improvements in all aspects of care.

11.1.2 Training

These data and international findings concur[236] in showing that generalist clinicians are usually uncomfortable with paediatric patients, especially infants and neonates. Undergraduate training in SA provides some paediatric training, but probably not enough, nor practical enough to meet the needs of generalists who are likely to see a good proportion of children in their daily practice.[356,357] In SA all newly qualified doctors are regarded as generalists and will spend their first years of practice as a generalist, often unsupervised and without mentoring and support from specialists. So long term recommendations would have to include better paediatric emergency and critical care training and exposure for undergraduates. Once qualified as a doctor, although there are continuing professional development programs, it is possible to practice as a generalist with little further training, exposure or updates outside of your own specific practice, and this is the case with many GPs in SA.

Internationally, there is an array of so called advanced life support short courses, including the paediatric specific courses, with widespread acclaim, and made mandatory by many employers and for further specialist training. Although there is not a great deal of evidence linking these courses to improved outcomes[358-362], anecdotally they equip clinicians with better skills and knowledge for managing everyday paediatric emergencies and wider dissemination of these courses is certainly a strong recommendation, since they focus on the initial resuscitation of the infant and young child. However, these courses are developed in HIC, and there are elements which may not be appropriate to LMIC, suggesting local, contextualized versions of these course, incorporating pre-course theory, hands on practical skills, and simulation based learning. These courses are largely targeted at medical practitioners, but there are also a number of courses aimed specifically at nursing staff, who are an integral part of the emergency team, and in many remote and rural settings, the nurses are the long term, experienced staff, while junior doctors are transient. So the experience and knowledge for emergency care may well come from the nursing staff. These course include Paediatric Life Support (PLS), a modified, shortened version of APLS, and IMCI and ETAT, although both the latter focus more on the identification and very early management and handover of the sick patient to a doctor or referral facility. Partly in response to the PTC findings, PLS courses have been rolled out over 2014 from RCWMCH, targeting nursing sisters from health facilities around the city, as well as now a compulsory component for UCT undergraduate medical students during their paediatric rotation. All these courses may improve skills, retention has been shown to be poor, unless there is frequent practice or ongoing training.[362]

In addition to resuscitation skills, the data point to flaws in the assessment of severity of young children. This is not an easy issue to tackle. Triage systems are designed to prioritize sick and injured children to be seen, they are not designed to identify the deteriorating child or the need for admission or PICU. Vitals signs in young infants and neonates are hard to interpret (even if you know the age appropriate ranges), and unlike in adults seldom show a linear deterioration – decompensation is often a rapid and terminal event in young children. The work on early warning systems[36,37,39,350,362] have had some success in HIC hospital settings, but have not resolved any one simple and effective tool to assess children. In fact other work[351,363] suggests clinicians gut feel might be as good as or better than other tools and signs. So there is no single solution to this entity, except perhaps more paediatric training, exposure, and access to experienced paediatric advice and support.

11.1.3 Continuity of Care

PTC data and methodology pointed to gaps in the continuum of care, which in many examples was more of series of steps of care, without linkage or communication. Better medical records, referral notes and records would seem to be a simple solution, and in the electronic age, digitization of records seems a tempting route. This may not yet be practical in this or other LMIC, but in the interim better emergency documentation needs to be encouraged (enforced), perhaps through preformatted clinical record forms, and referral letters, with an emphasis on the quality as well as quantity of documentation. We identified the immense utility of serial vital signs throughout a child's acute pathway, and documenting and transferring these onto subsequent facilities would seem an easy intervention.

A simple documentation instrument which contains key information in an easy to use format (including e.g. vital signs), with a copy which stays with a child throughout their pathway would be useful (as would documenting in existing documents retained by the patient such as the Road to Health card and possibly high risk cards). This will be developed with higher level care facilities and EMS. The design will draw on existing tools used in other areas of health care, such as WHO partograms and patient held growth charts. This component addresses a key failure identified in the current study where key information on critically ill children is either not obtained in each of the multiple health care facilities attended during the pathway, is apparently overlooked, or repeated - risking inefficient care and diverting resources and attention from acting on key danger signs or vital signs.

Another side of continuity of care is better communications between health care practitioners, and facilities. We identified that critical decisions (often around referral) were frequently delayed. And there was not always discussion with the receiving facility which serves not only to inform them of the patient, but also to get input and advice on initial management, most appropriate destination, and referral mode. Receiving facilities vary in their telephonic access, but it should be a priority to have a senior doctor at referring hospitals (be they district, regional or tertiary) available to take emergency referral calls. Communication between facilities and EMS was not always ideal and there needs to be more of a contiguous team attitude to the referral process rather than a discontinuous transfer of skills, management and monitoring. This may be accomplished partly by an attitude change (the child remains the responsibility of the referring clinician until passed onto the receiving clinicians); and partly through better communication channels (such as accessible telephonic access to receiving clinicians for advice and agreement on appropriate transfer mechanisms, and availability of senior EMS input on difficult/ delayed transfers) Handover to and from EMS personnel was not always performed, even for critically unstable children, and needs to be enforced from both sides.

11.1.4 Communication

Explaining to patients and caregivers what is wrong with their child, what the management plan is, and when and how referral might be effected was poorly done, especially at lower levels in the system, even though at lower levels there were fewer language issues between staff and patients. Improving these skills in healthcare professionals, and patients and caregivers demanding better communication may be a slow process to implement, and not directly linked to outcome, but is nevertheless vital and important in a patient centered system. Translators and improving practitioner's language skills should be part of this process

Nowhere was this clearer than the stories from the caregivers of patients who had died. Particularly at the lower facility levels, there was little or no explanation, let alone counselling to caregivers either immediately after the demise of their child, or at a later stage. The reasons for this are complex as discussed, it is always a stressful event for the clinicians, and in some cases they have no knowledge or insight into what was wrong with a child who died to offer. Protocols and systems for dealing with a child's death in a facility are urgently required, along with the resources and training they will need.[301,304] This will need to include support and debriefing for clinicians involved in the care of children who die in their hands, there was no evidence of this in the PTC data.

11.1.5 Paediatric Flow Management and regionalization

The data show that across facilities, there is no separation of paediatric patients from adults, with the consequences being that children are seen by generalists, prioritized alongside of adults, and managed in adult orientated settings (equipment, staff, and skills). In busy facilities, it would be easy to advocate that children should be seen separately to improve flow efficiency – channeled to a separate area, and assessed and managed by a separate team, familiar with children and their management and in a child friendly, age appropriately equipped setting. This will allow dedicated, high frequency paediatric care and improve not only the care for children, but the skills of the paediatric team. Perhaps a reality in some of the busier CHCs and hospitals, but not in most of the smaller and lower level facilities who do not see enough children to make this viable. One solution would be to regionalize paediatric emergency care, so that all paediatric emergencies are seen at specific dedicated sites, with skilled, specialized paediatric emergency care available, much as the RCWMCH is a dedicated paediatric hospital. Once this was implemented and marketed to the community and to referring health care workers, paediatric care would almost certainly improve at these centres. The negative impact would be that non paediatric designated facilities would deskill rapidly and loose the capacity to deal with any paediatric emergency, and distance to the dedicated paediatric centres would increase, making access more difficult. This is certainly a potential direction for future research, and would be a unique model in any setting, let alone a LMIC.

11.2 PAEDIATRIC AND PHC “SYSTEM” INTERVENTIONS

As part of the review process, partly to answer questions around the transition from long term care to acute care, reviewers identified health system issues which might have prevented the acute deterioration of children. The summary of these findings was given in Table 5-13, but are repeated here with just the longer term, non-emergency entities (Table 11-1), as almost every finding is a recommendation in itself, with much overlap into the main findings and other recommendations. These are largely not considered part of emergency or critical care, and more in the domain of PHC, paediatrics, community paediatrics and even public health.

Key recommendations from this list would include education of caregivers on discharge from neonatal services (this could include how and where to access emergency facilities, EMS access information and telephone numbers, and danger signs to look for in their children). Mothers already in the maternity and neonatal services are a “captive” audience and amenable to low cost educational interventions and strategies (some as simple as added information in the Road to Health booklet that records all the birth and follow on care for babies, retained by the caregiver). Early identification and stratification of high risk children (such as premature babies, congenital cardiac and chromosomal abnormalities) and other children with chronic health issues that may deteriorate rapidly or require specialized high level management (and the list could be endless HIV, renal disease, *etc.* and would require careful allocation and prioritization)). There have been attempts at this in the past – a so called “red card” system at RCWMCH alerted all health care practitioners (PHC, EMS, *etc.*) that a child had a certain condition and needed to be routed directly and urgently to RCWMCH if they presented in distress.

Other seemingly low hanging, high priority interventions might include identification of children with poor weight gain (it is remarkable that nearly every child admitted to PICU with severe illness was underweight); and strategies to manage caregivers who present repeatedly over a short period with the same child/ problem. Clearly the evidence from only critically ill children is not enough to address this issue, but there were many cases where the mother knew the child was sick and deteriorating but the illness was only picked up after repeat visits and deterioration.

Table 11-1 System Issues for intervention (non-emergency)

PRIMARY HEALTH CARE	Issues and potential interventions
Access to Care	Across peak times, trauma peaks, for foreigners, for out of province patients
	Reduced access/ investigations/ staff over public holidays/ festive season
	Integration and communication between PHC providers
Cardiac	Examination (pulse oximetry) of neonates prior to discharge
	Consideration of cardiac aetiology for respiratory distress
City Health	City Health Clinic accessing EMS issues
	Missing long term deterioration/ weight loss
General Practice	Communications with respect to referring patients
	EMS use by GPs
	Missing weight loss/ severity
Neonatal	Inadequate examination prior to discharge – NB anus, cardiac
	Access MOU/ integration with CHC/ Clinic
General Primary health Care	Missing deterioration especially loss of weight, poor weight gain
	Accuracy first diagnosis critical
	Follow up of high risk neonates, children; HIV follow up
	PHC nursing training
Community Health centres	Flow through CHC – lost in system
	Repeat visits to PHC for the same condition
	Senior access/ review
Parent	Lack understanding/ explanation long term conditions/ issues
	Parental HIV education
	Parental knowledge of danger signs
	EMS access knowledge and use
	First Aid/ CPR at home
CLINICAL	
System Wide	Hospital systems to ID/ escalate for critical patients
	Red Flag child with vomiting only, no diarrhea
	Red Flag awareness and seeking TB meningitis
	Feedback of post-mortem results to PHC/ family
	Documentation – especially date/ time/ name
	Triage – NB of respiratory rate, triage training and ancillary tests
TRANSFER and REFERRAL	
Emergency Medical Services	Inadequate utilization/ Availability of PFS/ ALS
	Paediatric (ICU) staff for long/ difficult transfers / Direct transfer system
RCWMCH	
	Communication between specialties and other facilities and services
	High Risk fast tracking
	Triage/ triage delays
	Short Stay Ward – admission criteria/ review/ protocols

ALS advanced life support; CHC community health centre; CPR cardiopulmonary resuscitation; EC emergency centre; EMS emergency medical services; Gastro gastroenteritis ; GP general practitioner; HCP health care provider; HIV human immunodeficiency virus; ICU intensive care unit; ID identification; OT operating theatre; PFS paediatric flying squad; PHC primary health care

11.3 Recommendations for Specific Levels

11.3.1 General Practitioners

Although relatively low numbers of PTC cases consulted GPs, and the quality of our assessment was limited by the available documentation, it was striking that GPs seem poorly equipped to deal with emergencies. They have little equipment or skills it seems, and are time pressured so the practice seemed to be to refer a child on as rapidly as possible without intervention, and often using inappropriate means such as suggesting public or personal transport rather than calling EMS. They are at the junction of the public/ private interface in these cases, and it will be a challenge to reach out to all the many practitioners, with little cohesion or overriding organization between them. Some suggestions would include education and marketing about the available public sector resources and facilities, including those of EMS.

11.3.2 Clinics

The clinic system in Cape Town (and in most SA settings) is not set up to deal with childhood emergency presentations, rather for routine "well baby" care such as growth monitoring and immunizations. However since they are the familiar facility, and often closer to homes, the data showed that many caregivers chose to wait for the office hours opening of these clinics for emergency care for their babies and children. There were no systems in place to stratify emergency presentations amongst the vast queues of "well babies", other than other parents allowing queue jumping, perhaps astute staff member's subjective assessment or parents who demanded help through various strategies. Consequently there were often prolonged delays in being seen. Although these facilities will not always have the resources and skills to manage these children, the priority in these clinics is early identification and timely referral to higher level facilities.

The high priority intervention was some sort of eyeballing, pre-triage assessment to separate emergency/ ill children, from those with routine issues. Since the completion of the data collection, and directly as a result of these findings, a tool has been developed and successfully implemented. It is still under evaluation, but known as the "Sick Children Require Emergency Evaluation Now" (SCREEN) tool, utilizing queue marshals, who ask simple questions of caregivers on entry to clinics, and fast tracking those identified to the nursing sister (personal communication, B. Hansoti, 2014).

Other key issues identified at clinics were access to EMS. Clinics seemed unaware of EMS systems (such as the PFS) and the different resources available and how to call for EMS assistance. This has already been addressed through simple measures of communicating EMS phone numbers and PFS information poster to City Health management for dissemination.

11.3.3 CHC

The CHCs in the study were the most frequently visited PHC level facilities (having no overnight admission capacity) by critically ill and injured children. These CHCs typically have an EC, but staffed by generalist medical officers, and after hours by junior doctors, locum medical officers, and generalists from various PHC disciplines doing their overtime hours. These are the facilities shown to be managing children with critical illness and injury relatively frequently – most daily or at least every few days, and are thus an important level to focus interventions on for maximal return.

Triage systems, although with their limitations (perhaps more so for young children and infants) are in place and seemingly effective at most CHCs, although there may be a role for reinforcing adherence to the SATS to ensure optimal utilization. Due to resource limitations, and the magnitude of adult illness as well as trauma (especially after hours and weekends) in CT, there is little or no separate streaming for children in most facilities and this would be ideal where numbers of children presenting warrants it – perhaps at peak times. As discussed above the CHC is the site where separation of paediatric care might be most effective; either at facility level (creating an entirely separate flow for children from adults) or by regionalization of paediatric care.

Once a caregiver and their child has negotiated through to actually being seen by a doctor, findings were that doctors were either unable to fully assess the severity of a child's illness (injury was seldom an issue to identify). These were generalists so largely not comfortable with small children, and despite the apparent numbers of critically ill children seen at facilities, individual practitioners likely see very few, and not enough to improve and/ or retain skills. Improving recognition of illness for such a practitioners is a challenge, and will likely require a multi-pronged approach including training (long term and short term (*i.e.* short ALS type courses); on site regular scenario based training, familiarity with age appropriate vital signs and their measurement (for example utilizing charts and documentation that uses a colour code for abnormal vital signs), and tools to help identify deteriorating and critically ill children.

Frustratingly, even in the scenarios where a doctor seemed to identify a really sick child, they did not have the skills, insights or ability to carry out an adequate resuscitation. The two common entities were the child in respiratory distress, needing ventilator support, but the clinician did not provide this (whether through lack of skills, equipment or self-confidence); and the child who was shocked and desperately need circulatory support and got little or inadequate (inadequate IV lines, late or no IO access, wrong fluids, inadequate fluids and most often a single bolus of fluids with no follow up assessment or continued therapy once this had been instituted and the child referred). Again this needs a multipronged approach: i) an environmental type scan to assess the available resources in facilities (be it equipment for resuscitation, structural issues (for example paediatric resuscitation distant from main resuscitation area), or human resource inadequacies (patient overload, staff insufficient (medical, nursing and ancillary) numbers and/ or seniority for the load); ii) collaborative input from all stakeholders to identify and address the issues; iii) training – be it through existing courses, or new specific courses developed for this context (with the insight of frequent presentations and failings), likely incorporating on site simulation based training which internationally is a growing educational trend with apparently positive effect[364-368]; iv) development of tools to monitor and assess improvement; v) better clinical protocols for managing common emergency conditions highlighted as major contributors to poor care outcomes.

Finally for CHCs, it was identified that frequently once children have had initial management (to varying degrees) and the decision is taken to refer, management and monitoring often dwindle or stop, the child now seen as the transfer/ receiving facilities entity. While EMS delays are not always an issue, they can be, especially around scarce ALS and PFS resources and management and monitoring in the interim can be critical and for a critically ill child requires a health professional providing ongoing care. Improving this care may be partly an attitude change, but there needs to mandated, regular, and documented reviews of the child by all practitioners (medical and nursing) until the child leaves a facility, with the emphasis that the responsibility for the patient remains with the referring practitioner until the child is transferred and received at the destination facility.

Some of the pressures and concerns for such a doctor, often the sole doctor in a facility after hours include time pressures, concerns over familiarity with invasive tubes/ needles/ fluid calculations, lack of follow on resources like ventilators/ ongoing monitoring/ EMS transfer resources.

11.3.4 District and Regional Hospitals

Although the data confirm that failings were less frequent at these level facilities, there were nevertheless gaps. Inadequate assessment and resuscitation were predominant, as in all levels, and would be amenable to all the same strategies as in the CHC, but possibly more easily implemented – higher frequency of critical paediatric patients, more on site skills (EM and paediatrics) and more experienced practitioners generally, as well as better resources.

Specific issues at these levels were delays – despite systems and resources apparently in place, and it will be necessary to look at specific institutions to uncover the locations and causes of delays in assessment, decision making and referral. Surprisingly frequent, was the issue of delayed or omitted antibiotic administration to septic or possibly septic infants and neonates, and this is surely easy to remedy through vigilance, enforced reminders on paperwork, referral forms and from other team members (nursing).

11.3.5 RCWMCH

Although the tertiary, specialized paediatric centre in the study, there were some surprising elements (perhaps not for RCWMCH staff) that this study highlighted. Management has accepted many of the study findings, and it will be incumbent on senior staff to ensure that interventions are carefully planned and thought through before hasty staff, bed and resource reallocations in response to some of the seemingly clear-cut findings and interventions. Although there were far less clinical failures, as would be expected in the specialist hospital, they were still present, and likely relate to junior doctors, relatively unsupervised after hours, highlighted not only by these data, but by Bonaconsa[69] who described the often chaotic imbalances between patient and staff numbers and severely ill children in the RCWMCH medical EC.

The biggest problems at RCWMCH regarded the delays from arrival in the emergency centre to admission to the PICU. Detailed process mapping will need to be undertaken to understand where the problems are and elements that the study has not revealed. Causes were multifactorial, for trauma patients often waiting for investigations (commonly CT scanning) and specialist assessment prior to PICU admission or theatre. For medical patients, often the decision to refer to PICU, and the acceptance by PICU were made early, and the delays were purely in accessing a PICU bed, and the consequent issues of critical care level monitoring in the interim in a busy EC. These problems should be addressed using a multidisciplinary team approach at the hospital. Interventions that are possible range from increasing the number of PICU beds through to improved management of patient flow through the hospital.

Attached to the RCWMCH medical EC is an overnight emergency ward, which the data also highlighted as a high risk area. Children assigned to this area are either likely well enough for discharge the following day, or are ill enough for further monitoring and assessment before a disposition decision is made, or sometimes are sent there because of overcrowding in the EC, and lack of beds in inpatient wards. So it a very mixed acuity ward, but without any high level monitoring, and overseen largely by junior doctors. This should be highlighted as a danger zone, requiring both tighter controls on who admits which children there (perhaps senior discussion/ assessment of every case admitted there), and more regular senior ward rounds, even after hours to spot the deteriorating child.

There was some concern over near miss cases and inadequate monitoring during radiological imaging and procedures, and these are amenable to policy and practice changes – monitoring equipment and personnel during imaging, training of radiology staff, and prerequisite stabilization, equipment and staff to accompany children during imaging.

Evidence showed that there were recurrent delays and more importantly inappropriate EMS crew/ vehicle arriving to transfer a critical child with consequent further delays or inadequate care for child. Implementation of a new prioritization for infants during the study had a clear positive impact on critical ill children, but of concern possibly a negative impact on other patients. EMS is currently in the process of implementing a new electronic management system which will have wide ranging changes and benefits to the system including electronic records, better dispatch systems, and facility communications. This would make an ideal transition stage for input from PTC findings. Areas for intervention might include the EMS dispatch system – understanding issues including call takers and their understanding/ prompting, specific call routing for Interfacility transfers of varying acuity, and information requested towards more appropriate and timely dispatch. Training and education of facility staff in when/ how to use which EMS resources for transfer – likely through some sort of proforma asking specific questions and helping to classify/ stratify acuity filled in by referring staff and handed on to EMS when they arrive at the facility with all relevant info now available on the proforma.

EMS has a commendable PFS system set up, and our data showed that this had positive impact on the quality of transfers when utilized. However dispatch criteria, the mechanisms for requesting and activating PFS may need further study, and perhaps simple interventions like marketing the system to health facilities. EMS data apparently suggests that the PFS crews and vehicles are underutilized, and this is alarming given the burden in the city. This needs review, and perhaps better integration with routine EMS transfers so that the PFS vehicles are dispatched by central dispatchers rather than by a separate system.

Although clinicians from health facilities were quick to criticize EMS for delays when called to transfer a patient, data suggests that EMS practitioners spend a considerable time on scene, even at health facilities where a child could be expected to be resuscitated and stable for transfer by the time of their arrival. This suggests facilities need to be better trained in resuscitating and preparing a child for transfer, as well as better communications between facilities and EMS to streamline the transfer of care, with an important upshot being less EMS time (and particularly that of scarce ALS resources) spent on scene, and EMS available for the next case sooner.

Fast tracking of patients

Although more of a system wide intervention, a fast tracking system might be implemented largely through EMS. Many patients were identified who were clearly critically ill at an early stage in there pathway, but still had to travel through a tortuous, and often delayed route to reach definitive care (PICU in most cases). It would be worthwhile to look at systems which facilitate bypass of facilities directly to the most appropriate higher level facility to improve care for carefully identified high acuity emergency patients. Perhaps along the line of direct transfer to PICU which do occur currently, but usually only between high level hospital and paediatricians. This would need criteria for the referring institution (perhaps based on the SATS and other novel assessment/management tools), and documentation instruments to highlight children in whom fast tracking is needed, and thus facilitate communication of severity with EMS. And would need to be carefully developed with a decision as to whether the receiving capacity for these fast tracked or direct transfers would be the PICU or the tertiary EC.

The simple solution to the largest time delay obstacle across the health system for critically ill and injured children that of PICU access, would be to provide more PICU beds. The argument from managers and administrators against this would certainly be that this is the most expensive component of the entire management of these children, and if better care were delivered prior to PICU admission that could prevent PICU admission or reduce PICU length of stay, this would be more cost effective. True as this might be, we have shown that improving care prior to PICU will require a multifactorial approach across a complex system, and likely take considerable time to implement and to see the improvements translate into a reduction in emergency PICU admissions. The short term, easy, single site, solution is clearly to increase the number of PICU beds available which would almost certainly translate to reduced delays across the system (most effective at the higher levels where the data have shown delays to be worst), improve patient load in the RCWMCH PICU waiting areas (EC and wards) and this would almost certainly translate to improved care across the spectrum of acuity and severity, and open the doors of the tertiary hospital to more critical referral (as well as lowering the thresholds for PICU admission). It will need careful economic assessment to realize the balance between strategies in this system.

11.4 RECOMMENDATION CONCLUSION

A mixed bundle of recommendations is presented, with varying priorities, time and resources required to design and implement many of them, listed in Table 11-2. Much work is still necessary to do this.

The high frequency of clinical failings in specific areas suggests priority areas for future interventions. In terms of assessment, more effective and objective ways of identifying and fast tracking acutely ill children especially in primary care settings are needed. In terms of acute management of sick children, particular diagnoses such as respiratory tract infections were both common and inadequately managed, suggesting an educational intervention could be focussed on a relatively small group of conditions, rather than a broad range of paediatric diagnoses. Rationalization (such as fast tracking of patients directly from primary care to PICU) and better prioritization of EMS services could improve referral delays, and review of the overall process and the system at the referral hospital, RCWMCH, would optimize scarce PICU resources. Improvement of patient flow in the tertiary hospital may be a crucial component of quality improvement for the overall pathway.

Table 11-2 Summary of Recommendations

SYSTEM WIDE

1. **SYSTEM WIDE**
   1.1. Proposal of a bypass, direct fast tracking system to high level care for high acuity children (direct to specific hospitals/ units *e.g.* PICU), with system wide integration (including EMS)
   1.2. Development/ reintroduction of high risk child identification system which identifies children at high risk of serious illness for priority care at specific sites ("red card system") to include premature babies, HIV, cardiac cases, chromosomal disorders etc.
   1.3. Documentation – flow info/ electronic records/ patient held/ proforma which encourage, enforce and improve the quality of emergency records
   1.4. Improved communication to caregivers – awareness, training, patient surveys
   1.5. Strategies to improve language barriers between HCP and patients: translators, language skills
   1.6. Maternity/ neonatal educational packaging – health facility access, emergency numbers, danger signs
   1.7. Consideration of broadening existing retrieval service from PICU to encompass specified, high risk transfers (and integrate to PFS and fast tracking systems)
2. **FACILITY WIDE**
   2.1. Address facility access and routing to paediatric emergency care at every facility level
   2.2. Develop and implement assessment and streaming of emergencies in non-emergency areas/ setups
   2.3. Awareness and identification of repeat visits in children with same problem
   2.4. Strategies for improving systems to identify and highlight children with weight loss and poor weight gain
   2.5. Strategies to improve access for caregivers – longer opening hours, better waiting periods, more efficient and effective triage
   2.6. Separation (or regionalization) of paediatric emergency care services
3. **CLINICAL** : training, tools, guidelines and processes to improve:
   3.1. assessment and identification of critically ill infants and neonates (especially in PHC facilities for generalists), including triage tools, early warning tools and existing tools (IMCI, ETAT, etc.)
   3.2. paediatric resuscitation – emphasis on infant, respiratory and septic presentations for all health care team (short course training for nurses (PLS), and doctors (APLS), as well as on site simulation training to maintain/ upskill)
   3.3. paediatric airway management
   3.4. early appropriate antibiotic delivery for sepsis and severe infection
4. **RESOURCES**
   4.1. paediatric specific resuscitation drugs and equipment
   4.2. Referral process
      4.2.1. Resources/ phone-lists/ helplines
      4.2.2. Paperwork proforma for ECs
      4.2.3. Protocols/ systems for phoning a receiving facility with a critically ill or injured
      4.2.4. Systems and resources to provide ongoing management and monitoring while await transfer

4.3. Training, processes and protocols for dealing with death of a child system wide (to include staff management, processed and feedback for family, guidelines around family presence at resuscitation, etc.)

5. EMS

5.1. Interfacility Transfer

5.1.1. EMS better communication of transfer needs from facilities/ info required on proforma/ dispatcher driven tools to better prioritize

5.1.2. EMS dispatch optimize response time

5.1.3. EMS dispatch – improve systems for appropriate crew/ vehicle/ equipment especially for inter-hospital transfers

5.1.4. EMS assessment/ stabilization prior to accepting cases and better handover DEMIST

5.2. EMS access to community – phone numbers/ marketing/ pickup points

5.3. EMS protocols for phoning/ radio ahead to facilities – only for red/ tubed/ critical?

5.4. PFS marketing and optimizing utilization of system (and dispatch systems)

6. RXH

6.1. Flow/ bed management to optimize PICU, high care and EC awaiting PICU bed usage and delays

6.2. ICU resources – increase emergency PICU bed capacity

6.3. Trauma process – improve processes and delays around CT/ neurosurgery/ theatre (head injuries common and processes can be planned ahead/ streamlined)

6.4. Senior Cover/ rounds in EC and overnight ward

6.5. Monitoring while await ICU

6.6. Monitoring during investigations (X-ray, CT scan)

7. CHC

7.1. Triage systems – improve for children, improve adherence

7.2. Separate streaming of children

7.3. ID, assessment and resuscitation training for clinicians (perhaps more of a priority here than at any other level)

7.4. Monitoring and management while awaiting transfer

8. City Health Clinic

8.1. Emergency training for all staff

8.2. Equipment – pulse oximetry/ HGT/ oxygen

8.3. Tools and processes for identification and streaming of acutely ill presentations from routine care

9. General Practitioners

9.1. Improve communications with public sector facilities and clinicians

9.2. Emergency training and equipment

9.3. EMS awareness and marketing programs

11.5 Follow Up Research

Further research must be focussed on implementation of changes (at individual institutions and systemically) with parallel assessment of compliance with change as well as effects on quality of care (primarily for critically ill children, but also for all other patients who may be affected by the change), cost effectiveness, and providers. Policy makers and healthcare managers in this environment have already been struck by the implications of assessing entire processes rather than individual components and it is our hope that implementation of changes across the system will be facilitated by provision of data and insights from this study.

Specific suggestions for ongoing research (some already initiated) include:

1. Ongoing implementation and validation of an early assessment tool at non-emergency facilities in and beyond CT (the SCREEN tool as described).
2. The search for an effective early warning tool which is easy to apply and identifies the sick and deteriorating infant, even at the PHC level is a priority. Analysis of vital signs may be helpful, but research to find other elements or a combination of factors would aid especially generalists in early identification of the deteriorating child.
3. Assessment of the long term outcomes of PTC patients to provide further data on the impact of the illness or injury on the children and their families in the long term.
4. Ongoing qualitative research on the PTC interview data which still holds a great deal of patient centred data which can provide many more insights to the issues and recommendation from caregivers.
5. Qualitative analysis of the specific subgroup of interviews with caregivers whose children died will provide unique insights to the circumstances and the manner in which the deaths were handled to help improve and develop guidelines for addressing managing the death of a child.
6. Environmental type scan to audit equipment and staff at target levels and facilities to address shortcomings as suggested by PTC data.
7. Studies looking at the feasibility and impact of electronic records and how this could provide retrospective clinical information about prior management data for receiving clinicians.
8. Using mapping technology, geographic information systems, to map the routes of critically ill patients, allowing geographic matching of resources to demand; as well as geographic identification of areas or facilities with particularly high incidences of specific presentations, and clinical failings.
9. EMS studies looking at the viewpoints of receiving and accepting facilities, as well as dispatchers to analyse the inefficiencies and frustrations in the dispatch system.
10. Qualitative studies looking at caregivers of children and why they would or wouldn't call EMS for a child with a medical emergency and how to address this without overwhelming the EMS system with non-critical children.
11. PICU retrieval teams – are they a reality in this and similar systems? Detailed review of critical transfers into the PICU and the associated adverse events may help to answer these questions.
12. Studies focusing on access to care, looking specifically at caregivers decision to seek help, and how and where they do this and how to improve on the delays herein.
13. Modification and streamlining of the PTC methodology to allow repeat studies in other settings, and in this system to monitor changes over time and following interventions.

Further research is likely to define the way forward for this type of confidential enquiry methodology, where it might be most effectively utilized and how. Implementation research is likely to be at the cutting edge of trialling improvements to the critical care pathway, and defining and measuring their impact on quality of care and outcome.

12 CONCLUSION

This is the first study to review clinical care of a large number of critically ill children from first presentation through to PICU or death, with high enrolment rates and using a detailed process to review cases from multiple aspects including the parents. The review methodology in this study has provided information on multiple aspects of quality of care and has highlighted the complexity of quality analysis in a healthcare system, and enabled identification of the relative contributions of critical care system failures along the whole pathway from initial health care contacts into PICU care, providing evidence about the interventions most likely to affect care at each stage

The study gives a detailed account of the pathway through the health care system for critically ill and injured children, with a unique emphasis on the caregiver's narrative and perceptions, detailing the unwritten experiences. The data allows mapping of the frequent routes of critically ill and injured children, as well as describing their demographic and health profile. A sample of children who died highlights issues around management of the unexpected death.

The fundamental challenge of this study was the measurement of quality of care. Even in a single unit of a facility, this is not easy and unless well proven and validated, can be a subjective measure open to criticism. This study endeavoured to measure quality of care across a health system, across a spectrum of levels of health services, resources and practitioners. This was done by: developing standards in an attempt to get end user input and buy-in to these as quality markers and indicators, formulation of a list of modifiable factors from various sources, measurement of time intervals, assessment of clinical outcomes at the final destination (PICU) for those who were admitted, and a blinded, expert panel review and consensus process to judge the quality of care, which is thought to be as rigorous a process as is feasible in any setting.

Results of the current study confirm and give evidence for many commonly held opinions about problems within the delivery of critical care. In addition to problems with clinical care, there are clearly problems at an organizational and structural level – these are particularly important because they can be addressed at relatively low cost (relative to clinical training). Up to now, however, no data existed on the actual problems faced by critically ill children in accessing care. This study has considerably expanded our understanding of the pathways to care for this group of patients: many of the findings will almost certainly be generalizable to other sick children, and to adults too, although this is was not explicitly investigated.

While health care in Cape Town is superior to that provided in many parts of the country or in the sub-Saharan region, the results can largely be extrapolated to these settings: the same problems will face providers of critical care for children in other large metropolitan settings. Moreover, the methods to assess these, intervene, and monitor progress of quality of care are going to be increasingly important for health care systems and policy makers in the many similar settings in LMICs.

The methodology of this study is directly repeatable in other settings, to provide an in-depth analysis of local problems with critical care. This novel method has shown that improvements in the quality and safety of care will require attention to the entire "pathway to care", and that even in a relatively well developed system there is significant potential for improvement with potentially significant reduction in both mortality and morbidity; and improvement in the utilization of expensive services such as PICU.

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APPENDICES

LIST OF APPENDICES

I. ETHICS APPROVALS (PATHWAYS TO CARE; PH PHD) 222

II. PROVINCIAL & CITY OF CAPE TOWN APPROVALS FOR RESEARCH 230

III. VISUALIZATION OF PATHWAYS AND REVIEWER GRADING 236

IV. PRESENTATIONS ON PTC WORK: POSTERS & CONFERENCE 243

V. PHD PROTOCOL – DEVELOPING A PATIENT CENTERED CARE PATHWAY FOR PAEDIATRIC CRITICAL CARE IN THE WESTERN CAPE 244

VI. PROTOCOL: PATHWAYS TO CARE FOR CRITICALLY ILL CHILDREN 261

VII. CASE STUDY (73) : SZ 274

VIII. CAREGIVER INTERVIEW SCHEDULE 287

IX. QUANTITATIVE DATA COLLECTED FOR EACH CASE 291

X. SCREENSHOTS OF ONLINE DATABASE 294

XI. PAEDIATRIC EMERGENCY CARE STANDARDS: 300

XII. MODIFIABLE FACTORS 310

XIII. VISUALIZATION OF EXPERT REVIEWER GRADINGS FOR EACH CASE 313

I. ETHICS APPROVALS (PATHWAYS TO CARE; PH PHD)

1) PhD: Developing a Patient Centred Critical Care Pathway for Paediatric Critical in the Western Cape; Health Sciences Research Ethics Committee, University of Cape Town
2) Renewal of above 2014-2015
3) Pathways to Care Research Project, Health Sciences Research Ethics Committee, University of Cape Town
4) Renewal of above 2014-2015
5) Oxford University Tropical Research Ethics Committee

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Faculty of Health Sciences Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

12 December 2012

HREC REF: 647/2012

Dr P Hodkinson
Division of Emergency Medicine
Department of Surgery
J-Floor
OMB

Dear Dr Hodkinson

PROJECT TITLE: DEVELOPING A PATIENT CENTERED CARE PATHWAY FOR PAEDIATRIC CRITICAL CARE IN THE WESTERN CAPE

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above mentioned study.

Approval is granted for one year till the 15 December 2013.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form, if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

pp **PROFESSOR M BLOCKMAN**
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

sAriefdien

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

sAriefdien

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30/11/2015
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	23/1/2015
Comments to PI from the HREC			

Principal Investigator to complete the following:

1. Protocol information

Date form submitted	Dec 2014		
HREC REF Number	647/2012	Current Ethics Approval was granted until	15/12/2014
Protocol title	Developing a Patient Centered Care Pathway for Paediatric critical Care in the Western Cape		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes x☐ No		
If yes, could you please provide the HREC Ref's for all sub-studies? **Note: A separate FHS016 must be submitted for each sub-study.**			
Principal Investigator	Peter Hodkinson		
Department / Office Internal Mail Address	Division of Emergency Medicine, Department of Surgery, J-floor, Old Main Building, Groote Schuur Hospital.		

HUMAN RESEARCH ETHICS COMMITTEE 23 JAN 2015 HEALTH SCIENCES FACULTY UNIVERSITY OF CAPE TOWN

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐x No
1.2 If the study receives US Federal Funding, does the annual report require full committee approval?	☐ Yes	☐x No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Faculty of Health Sciences Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

29 June 2011

HREC REF: 211/2011

Prof A Argent
Paediatric Critical Care
Red Cross War Memorial Hospital

Dear Prof Argent

PROJECT TITLE: PATHWAYS TO CARE OF THE CRITICALLY ILL CHILD.

Thank you for your thoughtful response.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 30 June 2012.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010)if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938) **This serves as notification of annual approval, including any documentation described below.**			
☑ Approved	Annual progress report	Approved until/next renewal date	30/7/2015
☐ Not approved	See attached comments		
Signature Chairperson of the HREC		Date Signed	13/11/2014

Comments to PI from the HREC
The letter dated 11th Nov 2014 is noted. Thank you

Principal Investigator to complete the following:

1. Protocol information

Date form submitted	11/11/2014		
HREC REF Number	211/2011	Current Ethics Approval was granted until	30/7/2014
Protocol title	Pathways to Care of the Critically Ill Child		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?	☐ Yes ☐✓ No		
If yes, could you please provide the HREC Ref's for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Prof A.C.Argent		
Department / Office Internal Mail Address	Division of Critical Care, School of Child & Adolescent Health, Red Cross War Memorial Childrens Hospital Andrew.argent@uct.ac.za		

HUMAN RESEARCH ETHICS COMMITTEE
13 NOV 2014
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

1.1 Does this protocol receive US Federal funding?	☐ Yes	☐✓ No
1.2 Does this study require full committee approval?	☐ Yes	☐✓ No
1.3 Has sponsorship of this study changed? If yes, please attach a revised summary of the budget	☐ Yes	☐✓ No

(Note: Please complete the Closure form (FHS010) if the study is completed within the approval period)

Oxford Tropical Research Ethics Committee

University of Oxford
Joint Research Office, Block 60
Churchill Hospital, Oxford OX3 7LJT
Tel. +44 (0) 1865 (5)72228, fax +44 (0) 1865 (5)72224
E-mail: fiona.goulthorp@admin.ox.ac.uk

UNIVERSITY OF OXFORD

Dr A Ward
Department of Primary Care Health Sciences
2nd Floor, 23-38 Hythe Bridge Street,
Oxford
OX1 8ET

29th June 2011

Dear Alison

Full Title of Study: Pathways to care for critically ill children

OXTREC Reference: 29-11

Thank you for your letter 28th June 2011, in which you have responded to the committee's request for further amendments, and included the revised documents:

Documents:	**Version:**	**Date:**
Participant Information Sheet	V2	25.06.2011
Participant consent form – Sick/Injured Child	V2	25.06.2011
Participant Consent Form - Deceased Child	V2	25.06.2011
Interview Schedule	V2	25.06.2011

I am therefore happy as Chairman for OXTREC to give approval for this study.

OXTREC would be grateful for annual and end of study reports in due course.

Yours sincerely,

Richard Mayon-White

Dr Richard Mayon-White

OXTREC Chair

Direct Line Tel: +44 (0)1865 (5)72224
Fax: +44 (0)1865 (5)72228 Email: fiona.goulthorp@admin.ox.ac.uk Web: www.admin.ox.ac.uk/rso/

II. PROVINCIAL & CITY OF CAPE TOWN APPROVALS FOR RESEARCH

1) Department of Health, Provincial Government of the Western Cape
2) City Health, City of Cape Town
3) Red Cross War Memorial Children's Hospital

DEPARTMENT of HEALTH
Provincial Government of the Western Cape

STRATEGY & HEALTH SUPPORT

healthres@pgwc.gov.za
tel: +27 21 483 9907; fax: +27 21 483 9895
1st Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP 83/2011
ENQUIRIES: Dr V Appiah - Baiden

Institute of Child & Adolescent Health
Red Cross Hospital
Klipfontein Road
Rondebosch
7700

For attention: Prof. Andrew Argent
Prof. Lee Wallis
Dr Peter Hodkinson

Re: Pathways to Care of the Critically Ill Child

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Kindly contact the following people to assist you with access to sites.

New Somerset Hospital	Dr Donna Stokes	(021) 402 6992
Victoria Hospital	Mr B Mashedi	(021) 799 1234
False Bay Hospital	Rob Martell	(021) 782 1121
Guguletu CHC	Ms Mabusela	(021) 637 1280
Hanover Park CHC	Ms Dziba	(021) 692 1240
Mitchells Plain CHC	Ms Z Xapile	(021) 391 5820
Retreat CHC	Mr H Lemmetjies	(021) 713 9741
Vanguard CHC	Mr L Mbanga	(021) 694 5540

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers once the referral sites have been identified, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwc.gov.za).

3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

DR T NALEDI
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 05 . 09. 201

CC	**DR K GRAMMER**	**DIRECTOR: SOUTHERN/WESTERN**
	DR J CLAASSEN	**DIRECTOR: KLIPFONTEIN/MITCHELLS PLAIN**
	DR L BITALO	**DIRECTOR: NORTHERN/TYGERBERG**
	DR G PEREZ	**DIRECTOR: EASTERN/KHAYELITSA**
	DR R CROUS	**DIRECTOR: EDEN**
		DIRECTOR: CENTRAL KAROO
	DR D DU TOIT	**ACTING DIRECTOR: OVERBERG**
	DR L PHILLIPS	**DIRECTOR: CAPE WINELANDS**
	DR C BESTER	**DIRECTOR: WEST COAST**

OF CAPE TOWN | ISIXEKO SASEKAPA | STAD KAAPSTAD

Civic Centre
12 Hertzog Boulevard
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Ref:
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Ifeksi: 021 421-4894

Burgersentrum
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Kaapstad 8001
Posbus 2815, Kaapstad 8000
Vra vir: Dr G H Visser
Tel: 021 400-3981
Sel: 083 298 8718
Faks: 021 421-4894

CITY HEALTH — Specialised Health

2011-07-29

re: Research Request: Pathways to care of the Critically ill child: Prof. Andrew Argent, Lee Wallis and Peter Hodkinson, Red Cross Hospital ID No: 10265

Dear Prof Argent,

Permission has been granted to do your research as per your protocol.

Eastern Sub District
Contact People

Dr P Nkurunziza (Sub District Manager)
Tel: (021) 850-4315 / 084 800 0644
Mrs N Mgqweto (Head: PHC & Programmes)
Tel: (021) 850-4312 / 084 222 1487

Kheyelitsha Sub District:
Contact People

Dr V de Azevedo (Sub District Manager)
Tel: (021) 360-1258/ 083 629 3344
Mr T Mhlubulwana (Head: PHC & Programmes)
Tel: (021) 360-1153/ 082 715 0147

Klipfontein Sub District:
Contact People

Mr K Nkoko (Sub District Manager)
Tel: (021) 630-1667/ 082 433 1332
Mrs T Nojaholo (Head: PHC & Programmes)
Tel: (021) 630-1626/ 084 220 0133

Northern Sub District:
Contact people

Mr A Zimba (Sub District Manager)
Tel/Cell: (021) 980-1230 / 084 627 2425
Mrs P Hendricks (Head: PHC & Programmes)
Tel/Cell: (021) 980-1211 / 084 300 0558

Mitchells Plain Sub District:
Contact People

Mrs S Elloker (Sub District Manager)
Tel: (021) 391-5012/ 084 222 1478
Mrs N Nqana (Head: PHC & Programmes)
Tel: (021) 391-0175/ 084 2221489

Southern Sub District:
Contact People

Mrs L Bakana (Sub District Manager)
Tel: (021) 710-8295/ 083 333 4942
Mrs B van Niekerk (Head: PHC & Programmes)
Tel: (021) 710-9383/ 082 821 7361

THIS CITY WORKS FOR YOU ESI SIXEKO SISEBENZELA WENA HIERDIE STAD WERK VIR JOU

Western Sub District:
Contact People: Mrs G Sifanelo (Sub District Manager)
Tel/Cell: (021) 514-4122 / 084 630 2903
Mrs M Stanley (Head: PHC & Programmes)
Tel/Cell: (021) 514-4124 / 072 329 6361

Tygerberg Sub District:
Contact People: Mrs M Alexander (Sub District Manager)
Tel: (021) 938-8279 / 084 222 1471
Mrs D Titus (Head: PHC & Programmes)
Tel: (021) 938-8281 / 084 308 0596

Please note the following:

1. All individual patient information obtained must be kept confidential.
2. Access to the clinics and its patients must be arranged with the relevant Managers such that normal activities are not disrupted.
3. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 3 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID Number (10255). Please use this in any future correspondence with us.

Thank you for your co-operation and please contact me if you require any further information or assistance.

Yours sincerely

pp Dr Visser

DR G H VISSER
MANAGER: SPECIALISED HEALTH

cc. Dr Nkurunziza & Ms Mgqweto
Mrs Alexander & Ms Titus
Mrs Elloker & Ms Nqana
Ms Bakana & Mrs van Niekerk
Mr Zimba & Ms Hendricks
Mr Nkoko & Mrs Nojaholo
Mrs Sifanelo & Mrs Stanley
Dr Azevedo & Mr Mhlubulwana
Dr K Jennings
Ms Caldwell

DEPARTMENT
of HEALTH
Provincial Government of the Western Cape

Red Cross War Memorial Children's Hospital

Tblake@pgwc.gov.za
Tel: +27 21 658 5788; fax: +27 21658 5166
Klipfontein Rd, Rondebosch, 7700
Private Bag X5, Rondebosch, 7701

REFERENCE:
ENQUIRIES: Dr. TA BLAKE

PROF A ARGENT
ICU
RCWMCH

Dear Prof Argent

PATHWAYS TO CARE RESEARCH PROPOSAL

The above mentioned research has reference.

The research has been approved provided tight control on patient folders is adhered to.
Should folders be requested from Medical Records, work should be done in the MR Department.
Should folders be requested to be removed, not more than five (5) folders may be removed at any one time. These folders will be signed for and returned by the end of the day (before 16h00)
No folders may be removed from the hospital premises.

Yours faithfully

[signature]

DR T A BLAKE
CHAIRPERSON
HOSPITAL RESEARCH REVIEW COMMITTEE
RCWMCH

25 July 2011
DATE

III. VISUALIZATION OF PATHWAYS AND REVIEWER GRADING

Table 0-1 is a summary table of the data pertaining to each PTC case (in the order they were collected), showing for each the main diagnosis, the expert reviewer gradings (global quality of care, and avoidability of death/ PICU/ severity), and the steps in the referral pathway. Each step is colour coded according to the level of the facility (for cases with more than 5 steps, the final cases have been shortened for brevity).

Table 0-1 Summary and visualization of each case gradings and pathway

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
1	M	**Cardiac**	G	-	NA	NA	RXH:1	RXH:2	RXH:3			
2	M	Other	F	-	PA	PA	Clinic:1	EMS:1	RXH:1	RXH:2	Op:1	RXH:3
3	M	Cardiac	F	-	NA	PA	Hospital:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
4	M	Pulm Infective	G	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
5	M	Cardiac	G	-	NA	PA	Hospital:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
6	M	Pulm Infective	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2		
7	T	Trauma	G	-	NA	PA	Hospital:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RX/EMS
8	T	Trauma	G	-	NA	NA	EMS:1	EMS:2	Hosp 2:1	RXH:1	RXH:2	
9	M	Pulmonary Obstr	F	-	NA	NA	Clinic:1	CHC:1	EMS:1	RXH:1	RXH:2	
10	M	Other	F	-	NA	NA	Hosp 2:1	EMS:1	RXH:1	RXH:2	Op:1	RXH:3
11	M	Other	F	-	AV	AV	CHC:1	EMS:1	RXH:1	Op:1	RXH:2	
12	T	Trauma	F	-	NA	NA	Hospital:1	EMS:1	RXH:1	RXH:2		
13	M	Pulm Infective	F	-	PA	PA	Clinic:1	EMS:1	RXH:1	RXH:2	RXH:3	RXH:4
14	M	Cardiac	F	-	NA	NA	GP:1	RXH:1	RXH:2			
15	M	Neurological	F	-	AV	AV	GP:1	RXH:1	Op:1	RXH:2		
16	T	Trauma	F	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
17	M	Pulm Infective	F	-	PA	PA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	Hosp 2:2	EMS/RX/ RXMS:3
18	M	Pulmonary Obstr	G	-	NA	PA	Hosp 2:1	EMS:1	RXH:1	RXH:2		
19	M	Sepsis	P	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
20	M	Pulm Infective	F	-	NA	NA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2
21	M	Other	F	-	NA	PA	EMS:1	RXH:1	RXH:2			
22	T	Trauma	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
23	M	Sepsis	F	-	NA	PA	EMS:1	RXH:1	RXH:2	RXH:3		
24	M	Cardiac	G	NA	-	-	RXH:1					
25	M	Sepsis	F	-	PA	PA	GP:1	CHC:1	EMS:1	RXH:1	RXH:2	
26	M	Pulmonary Obstr	F	-	PA	PA	EMS:1	CHC:1	RXH:1	RXH:2	RXH:3	RXH:4
27	M	Other	F	-	NA	PA	Clinic:1	RXH:1	RXH:2	Op:1	RXH:3	
28	M	Pulmonary Obstr	G	-	PA	PA	RXH:1	EMS:1	Hosp 2:1	EMS:2	RXH:2	
29	M	Sepsis	P	-	PA	AV	Hospital:1	EMS:1	RXH:1	RXH:2	RXH:3	
30	M	Neurological	P	-	PA	PA	RXH:1	RXH:2				
31	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	RXH:4
32	M	Cardiac	F	-	NA	PA	Clinic:1	EMS:1	CHC:1	RXH:1	RXH:2	RX/ RX
33	M	Other	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2	Op:1	RXH:3
34	M	Pulm Infective	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
35	T	Trauma	G	-	NA	NA	EMS:1	Private Hosp:1	EMS:2	RXH:1	Op:1	RXH:2
36	M	Cardiac	G	-	NA	NA	GP:1	CHC:1	EMS:1	RXH:1		
37	M	Other	F	-	NA	NA	GP:1	RXH:1	RXH:2			
38	M	Cardiac	F	-	NA	PA	RXH:1	RXH:2				
39	M	Pulm Infective	F	-	NA	PA	Hospital:1	EMS:1	RXH:1	RXH:2		
40	M	Pulm Infective	F	-	NA	PA	EMS:1	RXH:1	RXH:2			
41	M	Other	P	PA	-	-	EMS:1	CHC:1				
42	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
43	M	Pulmonary Obstr	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2		
44	M	Neurological	F	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
45	M	Gastroenteritis	F	-	NA	PA	CHC:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
46	M	Gastroenteritis	F	-	PA	PA	RXH:1	RXH:2				

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
47	M	Pulm Infective	F	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
48	M	Neurological	P	-	PA	PA	Clinic:1	EMS:1	CHC:1	RXH:1	Op:1	RX/ RX
49	M	Other	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2		
50	M	Neurological	F	-	NA	NA	clinic:1	Hospital:1	EMS:1	Hosp 2:1	EMS:2	RX/ RX
51	M	Cardiac	F	-	PA	PA	CHC:1	CHC:2	EMS:1	RXH:1	RXH:2	
52	M	Other	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
53	T	Trauma	F	-	NA	PA	EMS:1	RXH:1	Op:1	RXH:2		
54	M	Sepsis	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
55	M	Other	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
56	T	Trauma	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
57	M	Sepsis	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2		
58	M	Cardiac	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
59	M	Pulm Infective	F	-	PA	PA	GP:1	Clinic:1	EMS:1	RXH:1	RXH:2	
60	M	Cardiac	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
61	T	Trauma	F	-	NA	NA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
62	T	Trauma	F	PA	-	-	EMS:1	Hosp 2:1	EMS:2	RXH:1		
63	M	Cardiac	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
64	M	Cardiac	F	-	NA	PA	Clinic:1	CHC:1	EMS:1	RXH:1	RXH:2	
65	T	Trauma	F	-	NA	NA	EMS:1	RXH:1	RXH:2			
66	M	Gastroenteritis	P	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
67	T	Trauma	G	NA	-	-	CHC:1					
68	M	Pulmonary Obstr	F	-	NA	NA	RXH:1	RXH:2				
69	M	Pulmonary Obstr	F	-	NA	NA	EMS:1	CHC:1	EMS:2	RXH:1	RXH:2	
70	T	Trauma	F	-	NA	PA	CHC:1	EMS:1	RXH:1	Op:1	RXH:2	
71	T	Trauma	F	-	PA	NA	GP:1	EMS:1	RXH:1	RXH:2		
72	M	Cardiac	F	-	NA	PA	Clinic:1	RXH:1	RXH:2			
73	M	Sepsis	P	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
74	M	Pulm Infective	F	-	NA	PA	GP:1	RXH:1	RXH:2			
75	M	Pulm Infective	F	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	RXH:4
76	M	Cardiac	P	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
77	M	Sepsis	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
78	M	Cardiac	P	NA	-	-	RXH:1					
79	M	Sepsis	P	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
80	M	Pulm Infective	G	-	NA	NA	Hospital:1	EMS:1	RXH:1	RXH:2	RXH:3	
81	M	Cardiac	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
82	M	Other	P	-	PA	PA	Clinic:1	EMS:1	Hospital:1	EMS:2	RXH:1	RX/ OT/ RX
83	M	Sepsis	P	-	PA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
84	T	Trauma	F	-	NA	NA	EMS:1	RXH:1	RXH:2			
85	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RX/ RX
86	M	Neurological	P	-	PA	PA	EMS:1	CHC:1	EMS:2	CHC:2	CHC:3	E/H/E/R/O /R
87	M	Pulmonary Obstr	P	-	PA	PA	Hosp 2:1	EMS:1	RXH:1			
88	M	Other	P	-	NA	PA	Clinic:1	EMS:1	CHC:1	RXH:1	RXH:2	
89	M	Sepsis	P	-	PA	AV	Clinic:1	EMS:1	RXH:1	RXH:2	RXH:3	
90	M	Sepsis	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
91	M	Pulm Infective	P	-	PA	PA	Clinic:1	Hospital:1	EMS:1	RXH:1	RXH:2	
92	M	Sepsis	P	-	NA	AV	Clinic:1	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3
93	M	Neurological	P	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2		
94	M	Pulm Infective	F	-	PA	PA	CHC:1	RXH:1	RXH:2	RXH:3		
95	M	Pulm Infective	F	-	NA	NA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
96	M	Pulm Infective	F	-	NA	NA	RXH:1	RXH:2				
97	M	Pulm Infective	P	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
98	M	Pulm Infective	F	-	PA	PA	Private Hosp1	EMS:1	RXH:1	RXH:2		
99	M	Pulm Infective	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
100	M	Cardiac	G	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
101	M	Pulm Infective	P	-	AV	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
102	M	Sepsis	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
103	M	Pulm Infective	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
104	M	Pulmonary Obstr	F	-	NA	PA	RXH:1	RXH:2	RXH:3			

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
105	M	Pulm Infective	F	-	PA	PA	Clinic:1	EMS:1	RXH:1	RXH:2	RXH:3	
106	T	Trauma	F	-	NA	NA	RXH:1	Op:1	RXH:2			
107	M	Pulmonary Obstr	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1		
108	M	Pulmonary Obstr	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
109	T	Trauma	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	Op:/ RX
110	M	Pulm Infective	F	-	NA	PA	RXH:1	RXH:2	RXH:3			
111	M	Gastroenteritis	P	-	PA	PA	Clinic:1	RXH:1	RXH:2	RXH:3		
112	M	Pulm Infective	F	-	NA	PA	EMS:1	RXH:1	RXH:2	RXH:3	RXH:4	
113	M	Gastroenteritis	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
114	M	Sepsis	P	PA	-	-	CHC:1	EMS:1	Hosp 2:1			
115	M	Sepsis	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
116	T	Trauma	F	-	NA	NA	EMS:1	RXH:1	RXH:2			
117	M	Pulm Infective	F	-	NA	PA	RXH:1	RXH:2	RXH:3			
118	T	Trauma	F	NA	-	-	Hospital:1	EMS:1	RXH:1			
119	M	Pulm Infective	F	-	NA	PA	RXH:1	RXH:2	RXH:3	RXH:4		
120	M	Sepsis	F	-	PA	PA	Clinic:1	Hospital:1	Hospital:1	EMS:1	RXH:1	
121	M	Cardiac	P	-	NA	PA	Clinic:1	GP:1	RXH:1	RXH:2		
122	M	Sepsis	P	PA	-	-	CHC:1	EMS:1	RXH:1			
123	T	Trauma	F	-	PA	PA	EMS:1	RXH:1	RXH:2	RXH:3		
124	T	Trauma	F	-	NA	NA	EMS:1	RXH:1	RXH:2			
125	M	Cardiac	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
126	M	Sepsis	F	-	NA	PA	RXH:1	RXH:2				
127	M	Pulm Infective	F	-	NA	NA	Clinic:1	EMS:1	Hospital:1	EMS:2	Hosp 2:1	EMS/ RX/ RX
128	M	Other	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
129	M	Gastroenteritis	F	-	PA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
130	M	Pulm Infective	F	-	NA	PA	CHC:1	CHC:2	EMS:1	RXH:1	RXH:2	
131	M	Pulm Infective	F	-	NA	NA	Clinic:1	CHC:1	EMS:1	RXH:1	RXH:2	
132	M	Pulm Infective	F	-	NA	NA	RXH:1	RXH:2				
133	M	Gastroenteritis	F	-	NA	PA	CHC:1	CHC:1	CHC:2	EMS:1	RXH:1	RXH:2
134	M	Neurological	G	-	NA	PA	Private Hospl:1	EMS:1	RXH:1			
135	M	Other	F	-	NA	PA	EMS:1	RXH:1	RXH:2			
136	M	Pulm Infective	P	-	PA	PA	CHC:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
137	M	Pulm Infective	F	-	NA	PA	RXH:1	RXH:2	RXH:3	RXH:4		
138	M	Pulm Infective	F	-	NA	NA	MOU:1	EMS:1	RXH:1	RXH:2		
139	M	Pulm Infective	P	-	PA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
140	M	Neurological	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
141	M	Gastroenteritis	P	AV	-	-	CHC:1					

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
142	M	Pulm Infective	F	-	NA	PA	GP:1	RXH:1	RXH:2			
143	T	Trauma	G	-	NA	NA	EMS:1	RXH:1	RXH:2			
144	T	Trauma	F	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	Op/ RX
145	M	Sepsis	F	-	NA	PA	EMS:1	RXH:1	RXH:2			
146	M	Pulmonary Obstr	F	-	NA	NA	Private Hosp:1	EMS:1	Private Hosp:1	EMS:2	RXH:1	
147	M	Other	P	-	NA	PA	GP:1	RXH:1	RXH:2			
148	M	Neurological	P	-	NA	PA	EMS:1	CHC:1	GP:1	RXH:1	Op:1	RXH:2
149	M	Pulmonary Obstr	F	-	PA	PA	RXH:1	RXH:2				
150	T	Trauma	F	NA	-	-	Hosp 2:1	EMS:1	RXH:1			
151	M	Other	P	PA	-	-	CHC:1					
152	M	Sepsis	F	-	PA	PA	MOU:1	EMS:1	RXH:1	RXH:2		
153	M	Pulm Infective	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2	RXH:3	
154	M	Other	P	-	PA	AV	GP:1	RXH:1	EMS:1	Hosp 2:1	EMS:2	RX/ RX
155	M	Cardiac	F	-	NA	PA	RXH:1	RXH:2				
156	T	Trauma	G	-	NA	NA	Hospital:1	EMS:1	RXH:1	Op:1	RXH:2	
157	M	Pulm Infective	F	-	NA	PA	RXH:1	RXH:2	RXH:3			
158	M	Cardiac	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
159	T	Trauma	F	-	NA	PA	CHC:1	EMS:1	RXH:1	Op:1	RXH:2	
160	M	Pulm Infective	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2		
161	M	Pulm Infective	F	-	NA	PA	EMS:1	CHC:1	EMS:2	RXH:1	RXH:2	RXH:3
162	M	Pulmonary Obstr	F	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
163	M	Other	F	-	NA	PA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2
164	M	Sepsis	F	-	NA	PA	RXH:1	RXH:2				
165	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
166	M	Pulm Infective	P	AV	-	-	Clinic:1	RXH:1	RXH:2			
167	M	Pulm Infective	F	PA	-	-	RXH:1					
168	M	Sepsis	F	-	NA	PA	GP:1	RXH:1	RXH:2			
169	T	Trauma	G	NA	-	-	CHC:1					
170	M	Sepsis	F	-	NA	PA	GP:1	Hosp 2:1	EMS:1	RXH:1	RXH:2	RXH:3
171	M	Pulm Infective	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
172	M	Sepsis	F	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
173	M	Pulmonary Obstr	F	-	NA	PA	RXH:1	RXH:2	RXH:3			
174	M	Neurological	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
175	M	Pulm Infective	F	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
176	M	Pulm Infective	F	-	NA	PA	Clinic:1	EMS:1	Hospital:1	EMS:2	Hosp 2:1	EMS/ RX
177	M	Neurological	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
178	M	Pulm Infective	G	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1		

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
179	M	Pulmonary Obstr	P	AV	-	-	CHC:1	EMS:1	Hosp 2:1			
180	M	Pulm Infective	F	-	NA	NA	GP:1	Hospital:1	EMS:1	RXH:1	RXH:2	
181	M	Sepsis	F	-	NA	PA	Hosp 2:1	EMS:1	RXH:1	RXH:2	RXH:3	
182	M	Cardiac	F	-	NA	NA	GP:1	RXH:1	RXH:2			
183	M	Pulmonary Obstr	F	-	PA	PA	EMS:1	RXH:1	Op:1	RXH:2	Clinic:1	EMS/ RX
184	M	Pulm Infective	F	-	NA	PA	CHC:1	CHC:2	EMS:1	Hosp 2:1	EMS:2	RXH:1
185	T	Trauma	G	NA	-	-	EMS:1	RXH:1	Op:1			
186	M	Pulmonary Obstr	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
187	M	Gastroenteritis	F	-	NA	PA	RXH:1	RXH:2				
188	M	Cardiac	F	-	NA	NA	RXH:1	RXH:2				
189	M	Sepsis	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
190	M	Pulm Infective	F	-	NA	NA	Hosp 2:1	EMS:1	RXH:1	RXH:2	RXH:3	
191	M	Pulm Infective	G	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
192	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
193	M	Neurological	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
194	M	Pulm Infective	F	-	NA	PA	Clinic:1	EMS:1	Hospital:1	EMS:2	Hosp 2:1	EMS/ RX
195	T	Trauma	F	-	NA	AV	EMS:1	RXH:1	Op:1	RXH:2		
196	M	Pulm Infective	F	-	NA	PA	Clinic:1	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3
197	T	Trauma	F	-	NA	PA	EMS:1	RXH:1	Op:1	RXH:2		
198	M	Sepsis	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
199	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
200	M	Sepsis	P	-	PA	AV	Clinic:1	EMS:1	RXH:1	RXH:2	RXH:3	
201	M	Neurological	P	-	NA	PA	GP:1	Hospital:1	EMS:1	RXH:1	RXH:2	
202	M	Cardiac	G	-	NA	NA	Hospital:1	EMS:1	RXH:1	Op:1	RXH:2	
203	M	Pulm Infective	G	-	NA	PA	Hosp 2:1	EMS:1	RXH:1	RXH:2		
204	M	Pulm Infective	F	-	NA	NA	EMS:1	Hospital:1	EMS:2	Hosp 2:1	EMS:3	RXH:1
205	T	Trauma	F	NA	-	-	CHC:1	EMS:1	RXH:1			
206	M	Sepsis	F	-	NA	PA	CHC:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
207	M	Pulm Infective	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
208	M	Pulm Infective	F	-	NA	NA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2
209	M	Other	P	-	AV	AV	CHC:1	EMS:1	RXH:1	Op:1	RXH:2	
210	M	Sepsis	F	-	NA	PA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RX/ RX
211	M	Cardiac	G	-	NA	NA	RXH:1	RXH:2				
212	M	Pulm Infective	F	-	NA	PA	Hosp 2:1	EMS:1	RXH:1			
213	T	Other	F	-	NA	NA	RXH:1	RXH:2	Op:1	RXH:3		
214	M	Pulm Infective	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	Hosp 2:1	EMS:3	RX/ RX/ RX
216	T	Trauma	F	-	PA	PA	GP:1	RXH:1	RXH:2	Op:1	RXH:3	

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
217	T	Trauma	F	NA	-	-	EMS:1	Private Hosp:1	EMS:2	RXH:1		
218	M	Neurological	P	-	NA	AV	EMS:1	CHC:1	RXH:1	RXH:2		
219	M	Cardiac	P	-	NA	AV	CHC:1	EMS:1	Hospital:1	EMS:2	RXH:1	
220	M	Pulm Infective	P	-	NA	PA	Clinic:1	Hospital:1	EMS:1	RXH:1		
221	M	Other	F	-	NA	AV	GP:1	RXH:1	RXH:2			
222	M	Gastroenteritis	F	-	PA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
223	M	Sepsis	F	-	PA	PA	MOU:1	EMS:1	RXH:1	RXH:2		
224	M	Pulm Infective	F	-	NA	NA	Clinic:1	EMS:1	RXH:1	RXH:2	RXH:3	RXH:4
225	M	Pulm Infective	F	-	NA	NA	CHC:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2
226	M	Pulm Infective	P	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
227	M	Other	F	PA	-	-	Hosp 2:1					
228	T	Other	F	-	NA	NA	CHC:1	EMS:1	RXH:1	Op:1	RXH:2	
229	M	Pulm Infective	F	-	NA	NA	Private Hospl:1	EMS:1	RXH:1	Op:1	RXH:2	
230	M	Pulm Infective	F	-	NA	NA	Hosp 2:1	EMS:1	RXH:1	RXH:2		
231	M	Sepsis	P	-	PA	PA	Clinic:1	CHC:1	EMS:1	RXH:1	RXH:2	
232	M	Cardiac	F	-	NA	NA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
233	M	Other	F	NA	-	-	CHC:1					
234	T	Trauma	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
235	T	Trauma	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
236	T	Trauma	F	-	NA	PA	EMS:1	Hospital:1	EMS:2	RXH:1	RXH:2	
237	M	Cardiac	F	PA	-	-	EMS:1	RXH:1				
238	M	Pulmonary Obstr	G	-	NA	NA	RXH:1	RXH:2				
239	T	Trauma	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
240	M	Pulm Infective	P	PA	-	-	CHC:1					
241	M	Sepsis	F	-	NA	NA	MOU:1	EMS:1	RXH:1	RXH:2		
242	M	Other	F	NA	-	-	CHC:1					
243	M	Pulm Infective	F	-	PA	PA	Private Hosp:1	EMS:1	RXH:1	RXH:2		
244	M	Pulm Infective	F	-	NA	NA	RXH:1	RXH:2	RXH:3	RXH:4		
245	M	Sepsis	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
246	T	Trauma	G	-	NA	NA	CHC:1	EMS:1	RXH:1	Op:1	RXH:2	
247	M	Neurological	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
248	M	Other	P	-	AV	AV	Clinic:1	RXH:1	RXH:2			
249	M	Other	P	PA	-	-	Clinic:1	CHC:1	CHC:2			
250	M	Pulm Infective	F	-	PA	PA	Hosp 2:1	EMS:1	RXH:1			
251	M	Sepsis	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1	RXH:2	
252	M	Other	F	-	NA	PA	GP:1	RXH:1	RXH:2			
253	M	Other	F	-	NA	PA	EMS:1	Hosp 2:1	EMS:2	RXH:1		

Case	Medical/ Trauma	DIAGNOSIS	Global QOC	Avoidability of:			PATHWAY from Presentation to PICU (or death)					
				Death	PICU	Severity	Path Step 1	Step 2	Step 3	Step 4	Step 5	Step 6+
254	M	Pulm Infective	F	-	NA	PA	RXH:1	RXH:2	RXH:3			
255	M	Pulmonary Obstr	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
256	M	Pulm Infective	F	-	NA	PA	Private Hosp:1	RXH:1	RXH:2	RXH:3		
257	T	Trauma	G	-	NA	NA	EMS:1	Hosp 2:1	EMS:2	RXH:1		
258	M	Gastroenteritis	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
259	M	Sepsis	F	-	PA	AV	CHC:1	Private Hosp:1	Private Hosp:2	EMS:1	RXH:1	
260	M	Neurological	F	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
261	M	Other	F	-	NA	PA	EMS:1	RXH:1	RXH:2			
262	M	Pulm Infective	F	-	PA	PA	GP:1	EMS:1	RXH:1	EMS:2	Hosp 2:1	E/ R/R/R
263	M	Other	F	-	NA	PA	Clinic:1	EMS:1	Hosp 2:1	EMS:2	RXH:1	
264	M	Sepsis	P	-	PA	AV	RXH:1	RXH:2	RXH:3			
265	M	Gastroenteritis	F	-	PA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
266	M	Pulm Infective	F	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
267	M	Pulm Infective	P	-	PA	PA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	
268	M	Pulm Infective	F	-	NA	PA	Clinic:1	EMS:1	RXH:1	RXH:2		
269	M	Pulm Infective	G	NA	-	-	RXH:1					
270	M	Sepsis	G	-	NA	PA	RXH:1	RXH:2				
271	M	Pulm Infective	F	-	NA	NA	CHC:1	EMS:1	RXH:1	RXH:2	RXH:3	RXH:4
272	M	Cardiac	F	-	NA	NA	RXH:1	RXH:2				
273	M	Neurological	F	-	PA	PA	Clinic:1	EMS:1	CHC:1	RXH:1	RXH:2	
274	M	Neurological	P	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
275	M	Neurological	F	-	PA	PA	RXH:1	RXH:2	RXH:3			
276	T	Trauma	G	-	NA	PA	EMS:1	RXH:1	RXH:2			
277	M	Sepsis	P	-	NA	PA	CHC:1	EMS:1	RXH:1	RXH:2		
279	M	Sepsis	F	PA	-	-	CHC:1					
280	M	Other	F	-	NA	PA	EMS:1	RXH:1	RXH:2			
281	M	Gastroenteritis	F	PA	-	-	Hospital:1					
282	M	Other	F	NA	-	-	Hospital:1					
283	M	Sepsis	P	PA	-	-	CHC:1	EMS:1	RXH:1			
284	T	Trauma	P	PA	-	-	EMS:1	Hospital:1	EMS:2	RXH:1		

IV. PRESENTATIONS ON PTC WORK: POSTERS & CONFERENCE

Poster Presentations:

1. Paediatric Emergency and Critical Care –learning points and possible interventions from a longitudinal study of paediatric emergency care and referral pathways. African Conference on Emergency Medicine (ACEM) 2014, Addis Ababa. 1-3 November 2014.
2. Epistemological Crossroads on the pathway to care: Anthropological investigation of the 'Pathway to care' Initiative. Emergency Medicine Society of South Africa (EMSSA) 2013 Conference, Cape Town. 7 November 2013.
3. Pathways To Care Of The Critically Ill Child – A Nursing Perspective. World Congress of Critical Care (WFSICCM), Sun City. 29 August 2013.
4. Pathways to Care in Critically Ill Children: Evidence for Improving Paediatric Critical Care in South Africa. Evidence Live Conference, Oxford. 25-26 March 2013.
5. Pathways to Care in Critically Ill Children. School of Child and Adolescent Health Research Day, University of Cape Town, Cape Town. 23-24 October 2012.
6. Development of a Confidential Enquiry Process in South Africa: Pathways to Care in Critically Ill Children. International Conference on Emergency Medicine (ICEM) 2012 Conference, Dublin. 27-30 June 2012.
7. Development of Standards for Paediatric Emergency Care in Cape Town, South Africa. ICEM 2012 Conference, Dublin. 27-30 June 2012.

Oral Presentations:

1. Pathways to Care: A longitudinal patient centred investigation of critically ill and injured children in Cape Town. International Conference on Emergency Medicine (ICEM), Hong Kong. 13 June 2014.
2. Pathways to Care: Outcomes. Emergency Medicine Society of South Africa (EMSSA) Conference, Cape Town. 7 November 2013.
3. The Pathways to Care Research Project – A longitudinal patient centred investigation of critically ill and injured children in Cape Town, South Africa. World Congress of Critical Care Conference, Durban. 1 August 2013.
4. Pathways to Care in Critically Ill Children: Evidence for Improving Paediatric Critical Care in South Africa. Health Sciences Faculty Research Day, Stellenbosch University. 14 August 2013.
5. Pathways to Care: A longitudinal patient centred investigation of critically ill and injured children in Cape Town. Research Day, Department of Paediatrics and Child Health, University of Cape Town. 22 October 2013

V. PHD PROTOCOL – DEVELOPING A PATIENT CENTERED CARE PATHWAY FOR PAEDIATRIC CRITICAL CARE IN THE WESTERN CAPE

University of Cape Town

Division of Emergency Medicine, Department of Surgery

PHD PROJECT PROPOSAL

STUDENT: Dr Peter Hodkinson HDKPET001

SUPERVISORS: Prof Lee Wallis & Prof Andrew Argent

FIELD OF RESEARCH: Emergency Medicine/ Paediatric Critical Care

<u>DEVELOPING A PATIENT CENTERED CARE PATHWAY FOR PAEDIATRIC CRITICAL CARE IN THE WESTERN CAPE</u>

SIGNATURE:

Student: Dr Peter William Hodkinson Date:

SIGNATURES

We confirm that the above candidate presented a seminar on 31 October 2012 in the Department on the subject of this research proposal and we recommend that the proposal be approved.

Supervisor(s):

Date:

I hereby confirm that as Head of Department, I am of the view that the person(s) nominated as the Supervisor(s) is/are competent and has/have the time to supervise the PhD.

Head of Department: **Date:**

Introduction: Pathways to Care in Critically Ill Children Project

“Pathways to Care in Critically Ill Children” (PTC) is a research project currently underway based at Red Cross War Memorial Children’s Hospital (RCWMCH) , Cape Town. This is a collaborative project between the University of Cape Town (UCT) and Oxford University, funded by a Wellcome Trust grant.

The research is a longitudinal, patient centred analysis of the acute healthcare provided to critically ill and injured children in the Cape Town Metropol. This is performed by identification of emergency paediatric intensive care unit (PICU) admissions at RCWMCH, deaths in the RCWMCH emergency centre (EC) as well as deaths at a sample of nearby 24 hour community health centres (CHC). The study will run for 1 calendar year (November 2011- October 2012) and aims to collect data on close to 300 children. The caregivers of these identified and consented participants undergo a semi-structured interview, and medical records are collected from all facilities and for transfers from the acute presentation of the illness/ injury. This data is collated and entered onto an online database, and then reviewed by a panel of experts, comparing the care received at each level of the pathway to previously developed and agreed standards of care, identifying and grading major issues, and agreement on whether the death/ PICU admission as well as the severity was avoidable or not for each case. See Appendix A – Pathways to Care Research Project Protocol.

PhD Outline

As the clinical fellow employed full time on the PTC project, the PhD student has had major responsibility for implementing the PTC protocol, developing consensus standards for paediatric emergency care prior to the onset of the project, developing the review process and online database system. During the data capture, the role of the clinical fellow is clinical oversight of the entire process, and primary responsibility for the review of each patient once the data is collated. The review process is completed by a panel of experts (UCT leading experts in: Emergency Medicine, Paediatric Critical Care and Primary Health Care), with external review of selected randomized cases.

The PhD will be by publication and will include the following chapters. It is envisioned that the PhD student will be the first author in at least 6, and second author in at least 3 publications relating to chapters in the dissertation. The project is currently in the final data collection phase, hence the greater development in the initial chapters.

The outcomes of the PTC project present an immense volume of rich and valuable data to be analysed and used for various purposes to gain a better understanding and perhaps more importantly to develop real evidence based data rather than anecdotal information on the critical issues facing these children and their caregivers in accessing and obtaining health care. The elements selected for analysis and study in this PhD are by no means a conclusive analysis of the data and there are likely to be many concurrent and subsequent analyses of other aspects (especially using the qualitative interview data). The aspects chosen are those that particularly interested the student and seemed from the review of the first 2/3 of the data and some preliminary analysis to be of major importance and relevance. Particular emphasis has been laid on those aspects of the critical care pathways described that would seem to be amenable to improvement through practical and viable interventions rather than massive system changes as this will ideally be the follow on to this study.

PhD Aims & Objectives

The aim of this dissertation is to understand the barriers to critical care in the metropol and to propose how to mend these barriers.

The objectives are to analyse the data from the PTC study to show:

- Access to health care
- Compliance with standards of care across facilities
- Emergency Medical Services (EMS) accessibility and use
- Interfacility EMS access and care
- Quality of care at different facility levels
- Patient satisfaction and perception of care
- Identification of common and major care issues at different levels of care
- Delays in pathway to critical care
- Referral process/ communications and documentation
- Geographic visualization of disease and access to care

Data Analysis & Statistics

The PTC project has already begun setting up the analysis of the data through the online database, with the services of the IT specialist who developed the database, as well as through statistician employed within the existing project budget. Although most of the analysis is likely to use simple descriptive statistics, the expertise is there for in depth assessment. If additional expertise is required the services of other statisticians available through UCT and US will be sought.

Ethical Considerations

The current PTC research project has been given ethics approval by both UCT and Oxford: UCT - Human Research Ethics Committee: HREC 211/2011 and Oxford University – Oxford Tropical Research Ethics Committee: OXTREC 29-11.

A further ethics application is made to facilitate the PhD although only the data from the PTC project as accepted by the ethics committee’s will be used. All the ethical considerations of the initial PTC project will be followed, without any further data collection or patient/ caregiver interaction.

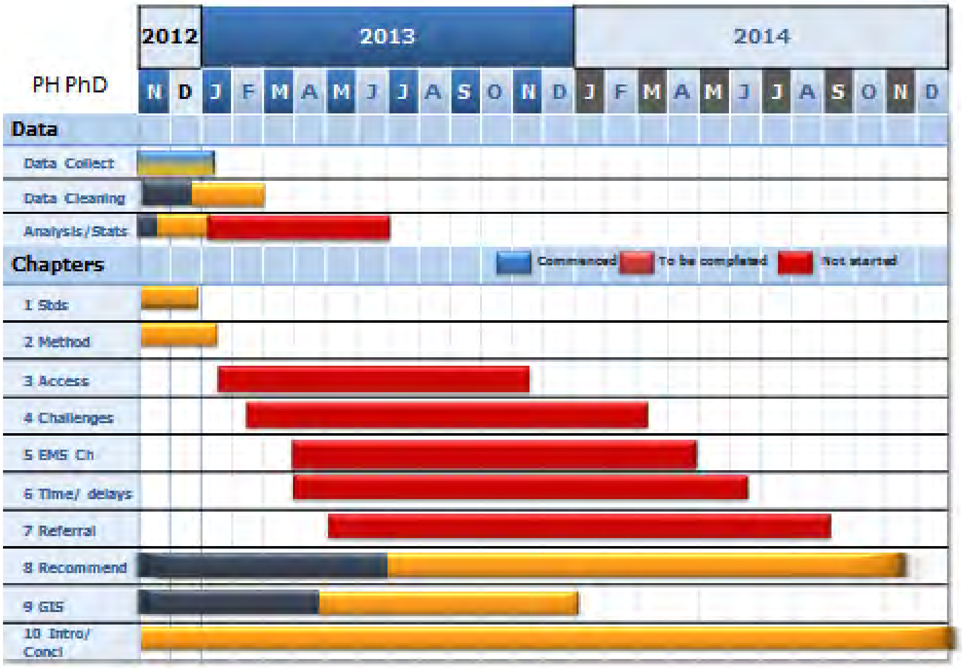
Resources

The PTC budget - Table 1 (although there have been some subsequent changes relating to the exchange rate *etc..*) provides for the data collection, review and analysis. This will cover the bulk of the envisaged resources of the PhD, although the student's time in the final analysis and write up phases is unlikely to be covered and will most likely be performed after hours/ part time for the remainder of 2013/2014.

Table 1: Pathways to Care Project Budget (as awarded by Wellcome Trust)

	Cape Town	Budget amount (Rand)	in GBP at 11
Staff	1 full-time research officer for 24 months to coordinate the study, consent, collect & enter all available electronic data.	R 520 000.00	GBP 47 272.73
	2 full time data collection clerk (pay class 6) copying medical records for 15 months including training	R 362 500.00	GBP 32 954.55
	2 full-time translators (1) Xhosa and (1)Afrikaans for interviews (pay class 5) - 15 months including training.	R 300 000.00	GBP 27 272.73
	1 full-time interview coordinator (pay class 8) to supervise and oversee the interviews - 18 months.	R 254 943.60	GBP 23 176.69
	Clinical fellow to develop standards and protocols, review medical records and perform data extraction weekly for 2 years	R 1 227 342.00	GBP 111 576.55
	Clinical sister to help Rencia with data integration and processing (Pay class 7), for 1 year part time	R 275 000.00	GBP 25 000.00
	Senior Finance Officer to coordinate the funds management within UCT and draw up financial reports.	R 13 051.30	GBP 1 186.48
	Purchasing Officer raises purchase orders	R 9 107.20	GBP 827.93
Travel	Travel for local study supervisors to go to Oxford in the third year.	R 50 000.00	GBP 4 545.45
	Travel costs weekly to collect medical records	R 45 000.00	GBP 4 090.91
	Travel for interviewers to conduct interviews	R 12 000.00	GBP 1 090.91
Consumables	Advertising posts	R 20 000.00	GBP 1 818.18
	Training for staff - statistics, qualitative data analysis	R 20 000.00	GBP 1 818.18
	tapes, tape recorders, computer, programmes, stationary, phone costs, filing cabinets	R 50 000.00	GBP 4 545.45
Total:		**R 3 158 944**	**GBP 287 176**

Timeline: Gannt Chart



Appendices

A. Pathways to Care Research Project Protocol
B. Synopsis Protocol: Pathways to Care Project
C. Ethics Approvals:
D. UCT (for PHD) - Human Research Ethics Committee: HREC 647/2012
   UCT - Human Research Ethics Committee: HREC 211/2011 & Annual Report 2012.
   Oxford University – Oxford Tropical Research Ethics Committee: OXTREC 29-11.
E. Institutional Approvals:
   Department of Health, Provincial Government of Western Cape RP 83/2011

   Red Cross War Memorial Children's Hospital

   City Health, City of Cape Town 10255

   Tygerberg Academic Hospital

PHD PROTOCOL CHAPTER OUTLINES:

1. STANDARDS FOR PAEDIATRIC EMERGENCY CARE 251
2. METHODOLOGY/ DEVELOPMENT OF PTC STUDY 252
3. ACCESS TO CARE FOR CRITICALLY ILL CHILDREN 254
4. CHALLENGES TO PAEDIATRIC CRITICAL CARE 255
5. CHALLENGES FOR EMS IN PAEDIATRIC CRITICAL CARE 256
6. TIMELINES & DELAYS 256
7. REFERRAL SYSTEM 257
8. RECOMMENDATIONS/ IMPLEMENTATION PLANS 257
9. GEOGRAPHIC/ GIS MAPPING OF PROJECT DATA 258

1. Standards for Paediatric Emergency Care

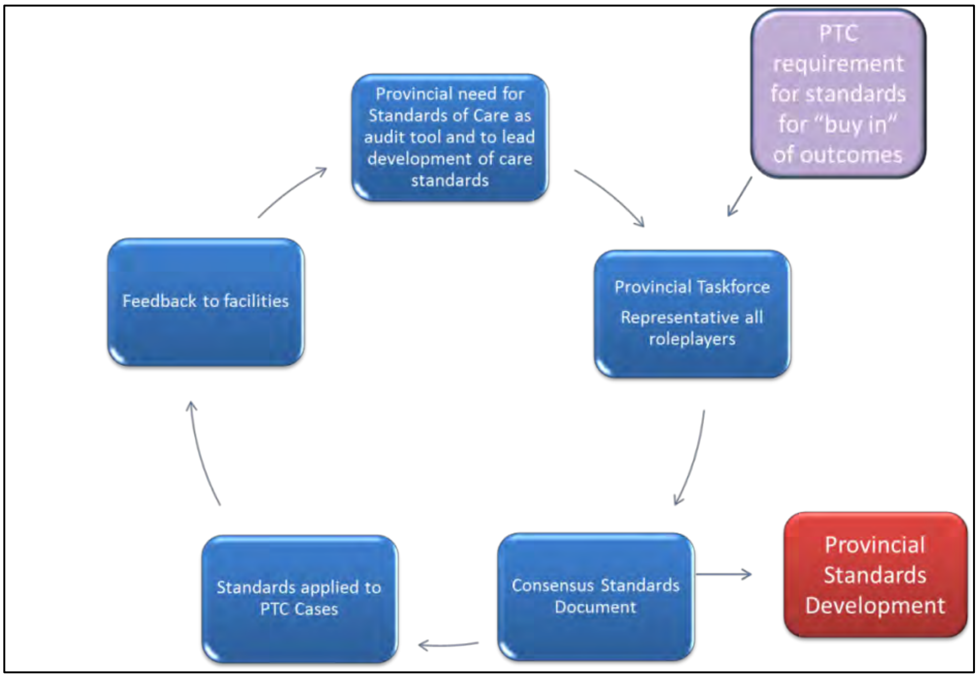
Internationally, standards of care have been a useful instrument to allow benchmarking and consequent improvement of structure and process in health systems.

Prior to the commencement of the PTC study, it was determined that there was a need to develop clear, objective standards for paediatric emergency care in the Cape Town metropol, with a particular requirement that these be developed by consensus with input and agreement from all levels of facilities and disciplines involved. It was believed that this would facilitate "buy-in" by all stakeholders to the outcomes of the study, one aspect of which would measure compliance with the agreed standards. The standards would allow for quality assurance and improvement and the intention would also be to spur the development of more comprehensive provincial/ national standards. A taskforce group was formed with representation from all involved with paediatric emergency care to developed standards. Included were representatives from paediatrics, emergency medicine, trauma, made up of managers, doctors, nurses and paramedics from clinics, health centres, and hospitals. Fig 1 is a schematic of the development and utilization of such standards.

A workforce was convened, and initially using internationally and locally accepted resources, drafted and refined into a set of standards through several consensus meetings. The standards developed are applicable to all levels, with focus on emergency conditions that commonly involve an ultimate critical care element under the following subsections:

- reception and resuscitation,
- gastro-enteritis,
- respiratory distress,
- septic shock,
- coma/ convulsions,
- polytrauma/ head injury,
- burns, and
- referral & ICU access.

Fig 1 Schematic of Standards Development and Implementation



The consensus standards reached by this brief and accelerated process represent a meaningful tool for audit and quality assurance. By involving all role-players at an early stage in the consensus process, the standards are given local credibility and attainability.

We present a set of standards which will spur the development of further standards; allow objective quality assurance; and facilitate research into the healthcare system, consequently improving the quality of emergency care for children in the province.

This process of developing standards was completed prior to the onset of the PTC project. The process was led by the PhD student and will be described in a first author paper for publication.

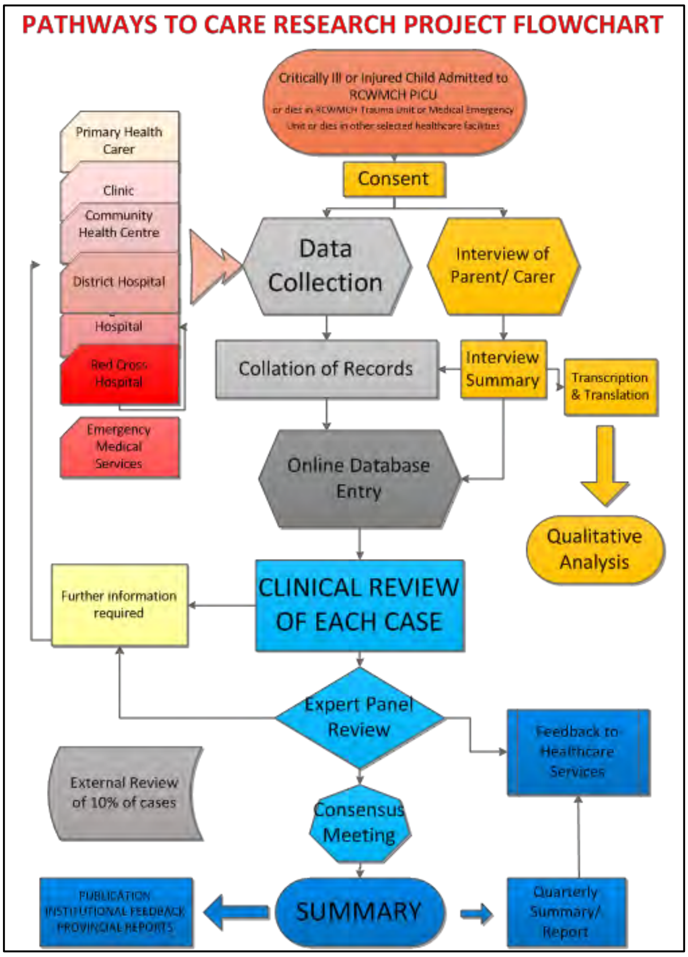
2. Methodology/ Development of PTC Study

When, where, and how often does care for critically ill children fail? There is a lack of evidence about the relative importance and frequency of care failures at different points in the care pathway which is crucial in prioritising allocation of resources to achieve improvements in critical care and a reduction in child deaths.

To address these problems known to exist but without any quantification or evidence of the scale or level of the issues, a research program was developed using a novel combination of qualitative and more mainstream quantitative methodology. This was based initially on the methodology of the UK style "Confidential Enquiry" into maternal mortality and paediatric mortality, where there is an in depth investigation of the records and circumstances around a death and a panel consensus is reached as to the main issues and potential remedial factors to prevent the recurrence and learn from the errors of the system.[1,2] In addition to this framework, the project would incorporate the assessment of standards of paediatric emergency care (developed in parallel) which would allow an objective assessment of the care (at a standard which all parties involved in the care pathway have contributed to and agreed is possible) as well as an interview with the parent/ caregiver of each child studied.

Methodology: A sample of emergency admissions to the Red Cross War Memorial Children's Hospital Intensive Care Unit and paediatric death will be ascertained over a one year period. Data will be obtained on all aspects of the pathway - from onset, primary health care, hospital emergency management and EMS transfer to ICU admission or death, through review of medical records, and semi-structured interview with carer.

Fig 2 Project Flowchart



The process for each included case (Fig 2) will include a semi-structured interview of the caregiver of the child, and collection of the medical records from all facilities/ ambulance services for the acute healthcare presentation and "pathway". An electronic database has been developed which facilitates the entry of all this data, at which stage a clinical review is performed by an emergency medicine expert. This review will summarize the interview and medical information, develop a clear timeline of the pathway, and then compare the care at each facility to the consensus standards of care. Further issues or “modifiable factors” will be identified and graded for their impact on the outcome of the child. The final element of the review process assesses the quality of care at each facility, and the avoidability of death/ ICU admission and severity at the time of ICU admission. Each case is reviewed by the clinical fellow, followed by three local experts in Paediatric Critical Care, Emergency Medicine and Primary Health Care (each blinded to the other’s gradings), after which the database indicates whether there is consensus according to an algorithm. If not, the case is discussed at a consensus meeting until agreement is established.

Importance of This Study: This presents a novel approach to identifying and quantifying flaws in the healthcare system at all levels. It is immensely more difficult to analyse multiple systems rather than individual facilities and we believe this case based approach will prove powerful and informative and offer a model for systems research elsewhere.

This section will form a chapter of the dissertation, as well as a publication (likely second authorship). Although the PhD student played a role in the later stages of implementing the protocol and developing the review process, the PTC protocol and methodology was put together largely by the PTC principal investigators.

3. Access to Care for Critically Ill Children

Background: The PTC project provides a unique patient centred perspective on access to care, an element which has not been well studied in this population to date. The information from the caregiver of each child will give a clear picture of the difficulties and issues that parents of ill and injured children face in seeking healthcare in the metropol, as well as a patient centred perspective on the perceptions of accessing health care.

Aspects which anecdotal and pilot data suggest will be informative and give important direction for strengthening the health system include:

Caregiver access to healthcare:

- EMS use for critically ill and injured children by home/ caregivers – knowledge/ barriers/ challenges
- Health facility access issues – local *vs* distant, type of facility first accessed/ after-hours access
- Medical *vs* trauma *vs* disease specific access issues
- Traditional Healers/ herbalists – impact in urban paediatric population
- Urban *vs* rural access to care – are patients from rural areas accessing urban care directly (e.g.E.Cape “healthcare refugees”)

Emergency access within healthcare facilities:

- Initial screening/ assistance (“gatekeeper” role)
- “eyeballing” or initial rapid assessment of incoming patients to identify urgent cases

- Triage – in place/ functioning/ validity across presentations and age range
- Referral system - communications between facilities/ health care providers/ EMS interfacility transfer issues/ practicalities.

Much of the existing (and largely anecdotal) understanding of paediatric patients' access to care is from the healthcare practitioner's point of view with a tendency to blame late and advanced presentations on parents' lack of knowledge/ insight/ care for their children. It is likely that this approach underrates the obstacles and barriers to care for sick children, even when illness is correctly identified by parents/ caregivers.

Understanding these issues may suggest simple and cost effective system changes or modifications such as publicity campaigns, maternal education on access post-delivery and even in EMS activation/ dispatch systems. It is likely that many of these issues have overlap with adult emergency access to care, as well as extension to other health systems in SA and in other developing settings.

This will form a chapter, and at least one first author publication.

4. Challenges to Paediatric Critical Care

Data from the PTC project provides a unique longitudinal view across different health structures and systems to allow identification of the obstacles experienced in the care of critically ill children. Preliminary analysis of the early data suggests that as many as 30% of the PICU admissions were thought to be potentially avoidable, with an even more concerning 70% of cases thought to have arrived at PICU with a potentially avoidable severity of illness. So there is clear evidence already for the problems in the pathway to care and a grave need to identify, analyse and explore the issues.

Some of the envisioned analysis will look at specific aspects around quality critical care, with a focus on common and high acuity problems identified around the following themes:

- System Wide Issues – are their universal issues that negatively affect paediatric pathways to care?/ training in paediatric emergency care?/ structures and equipment for children/ flaws in adult dominated healthcare system perhaps?
- Facility level issues – are there common issues to specific levels of facility/ geographic area/ referral networks?
- Disease Specific issues – does the system provide better/ worse care for some diseases than others? Common/ uncommon/ seasonal/ protocol based care/ age specific care
- HealthCare Providers – training/ supervision/ access to guidance/ seniors/ after-hours services/ locum practitioners
- Issues which impact outcome
- Communication with patients/ caregivers – does anyone in the system do this well? If so who and how and what can be learnt

- End of life care issues for children – it is expected that around 20% of the PTC cases will have died during or shortly after accessing the healthcare system and it is inevitable that dealing with the caregivers around end of life issues is part of the analysis not just the care of the dying child.
- Documentation – what are the crucial issues that health care providers (HCP) need to document – medico legally/ clinically/ for continuum of care and how well do different practitioners do on documentation?

This will form a chapter and likely several first and possibly several second authorship papers as the bulk of the analysis of the PTC data lies in this domain.

5. Challenges for EMS in Paediatric Critical Care

In addition to the system wide challenges detailed under the previous header, the PTC data provides much insight to the EMS system for paediatric critical care, and the strengths and failures of the system. Despite a relatively well resourced service which has a dedicated "Paediatric Flying Squad" to transfer critically ill children (largely neonates/ infants), the system has flaws.

Issues that will come out of the data and provide insights for planning and optimizing the system include those where there were clear issues with the EMS service provided and these will be analysed and discussed with themes such as:

- EMS access – although addressed more generally in the "access to care" section there is more information from this data and especially on the access for inter-facility transfers where the majority of the PTC EMS services took place.
- EMS dispatch: caller info/ prioritization/ delay/ crew allocation – again with special emphasis on interfacility transfer – should there be a separate access/ dispatch system? How to manage prioritizing conflicting calls from a facility *vs* a scene/ home call, and adult *vs* child often.
- EMS appropriate skills and resources for paediatric transfer
- EMS clinical management issues
- EMS communication with patient/ caregivers

This will form a chapter and likely several first author publications, as well as some publications with overlap to the previous chapter publications.

6. Timelines & Delays

Paediatric critical care has much overlap with adult critical care, but the overriding important difference is perhaps the rapid deterioration of children and hence the importance of the timeline and delays to care.

This chapter will concentrate on developing an understanding of the delays in the pathway to care, as well as assessing their impact. Analysis will reveal the common issues and bottlenecks in the pathways to care with much information expected to increase understanding around these delays, their causes, and effects.

- Timelines & Delays – are their delays/ are they reasonable/ preventable/ do they affect outcome/ delays relative to referral pathway/ EMS pathway

- Continuity of Care *vs* Continuum of Care
- Where are delays and do they impact outcome
- Tackling major "holdups" for individual patient flow to critical care
- System Wide "holdups" e.g. access to PICU

It is expected that there will be a first authored paper from this section, perhaps with overlap from sections 4,5, and/or 7.

7. Referral System

The vast majority of enrolled PTC patients are referred through at least one if not two facilities en route to critical care. Is the transfer of the critical patient from one team to another managed optimally? There is the potential for repetition of many facets of the care and management, but also for information and continuity of the resuscitation to be lost. In this chapter the analysis will provide information on when and where the referral system failed and how to address these failures. Issues to be explored include:

- Documentation – existing proforma/ common gaps in referral documentation/ required *vs* desirable information
- Flow of information
- Referral Letter
- Telephone Discussion/ Referral
- EMS communications with receiving facility
- Internal Communications

First author publications from this chapter are envisaged, perhaps in conjunction with chapters 4,5,and/or 6.

8. Recommendations/ Implementation plans

This penultimate chapter is perhaps the most important to tie together the major findings of the PTC study and to make recommendations that are sound yet practical based on all the findings. A grant has been put in for funding some implementation on the preliminary findings of the PTC study already and this will hopefully be the next phase of the project, but there are additional recommendations some easy to apply at facility/ district levels, and some much longer term and harder to implement that will need provincial if not national support/ buy in. Of note is that although the study has had a purely paediatric focus, many of the findings will likely be common to adult critical care and there will undoubtedly be positive spin offs benefitting adults in the system, be they through optimizing EMS inter-facility transfers, in referral processes, or even in better documentation through the pathway.

The recommendations are likely to focus around:

- Major findings from PTC data and preliminary analysis of the first 100 cases would suggest areas such as:
  - Tools and training to prioritize critically ill children in non-emergency areas
  - Provision for direct referral of pre-identified children to high level/ tertiary care

  - Tools for assessment of severity of critically ill children at primary health care level
  - EMS inter-facility transfer – optimization of dispatch system, as well as co-ordinated education/ marketing of the system to facilities requesting interfacility transfers.
  - RCWMCH – optimization of EC flow management
  - Documentation – education and systems such as proforma which encourage/ support/ force documentation of relevant information
  -
- Relate to potential implementation, be they:
  - Training
  - Resources (human/ structural/ equipment)
  - Protocols
  - System Improvement
  - Audit/ clinical governance

It envisaged that with the appropriate funding and support this chapter will be a framework to the implementation process, but likely publications will be part of the next phase.

9. Geographic/ GIS mapping of project data

The PTC database includes geo-coded locations (*i.e.*latitude/ longitude) for the home of each enrolled child, as well as those of the scene of accidents. Combined with available geo-spatial resources such as facility locations and street mapping, this provides a rich platform for geographic analysis of many issues relating to the data. Simple freeware such as GoogleEarth and QGIS allow visual representation of the data as well as more advanced analysis. Some of the analysis that is likely to be gained from the geographic analysis:

- Visualization of where our patients live
- Visualisation of the pathway(s) through the health care sector
- Distribution of RXH population/ specific populations such as trauma/ medical/ specific disease entities and relating any of these to socio-economic areas.
- Road distance to facilities – can be analysed on individual case basis or on population scale
- Physical route distances between facilities *vs* referral protocols
- Visual mapping of quality of care/ outcome for different facilities/ areas
  I.e. to gauge where most of our sick patients come from and where the failures in the system occur
- More complex network analysis requiring the assistance of a GIS expert

Preliminary data for the first 100 PTC cases entered onto Google Earth has enabled the following examples of the visualising potential for Fig 3 – all cases, and Fig 4 – an individual patient's "pathway to care".

The GIS outcomes will be published initially as a first author paper describing the visualizations of the data, and with collaboration with GIS expertise both locally and internationally there will undoubtedly be subsequent analysis and publications.

Fig 3 GIS Mapping of PTC Project initial data

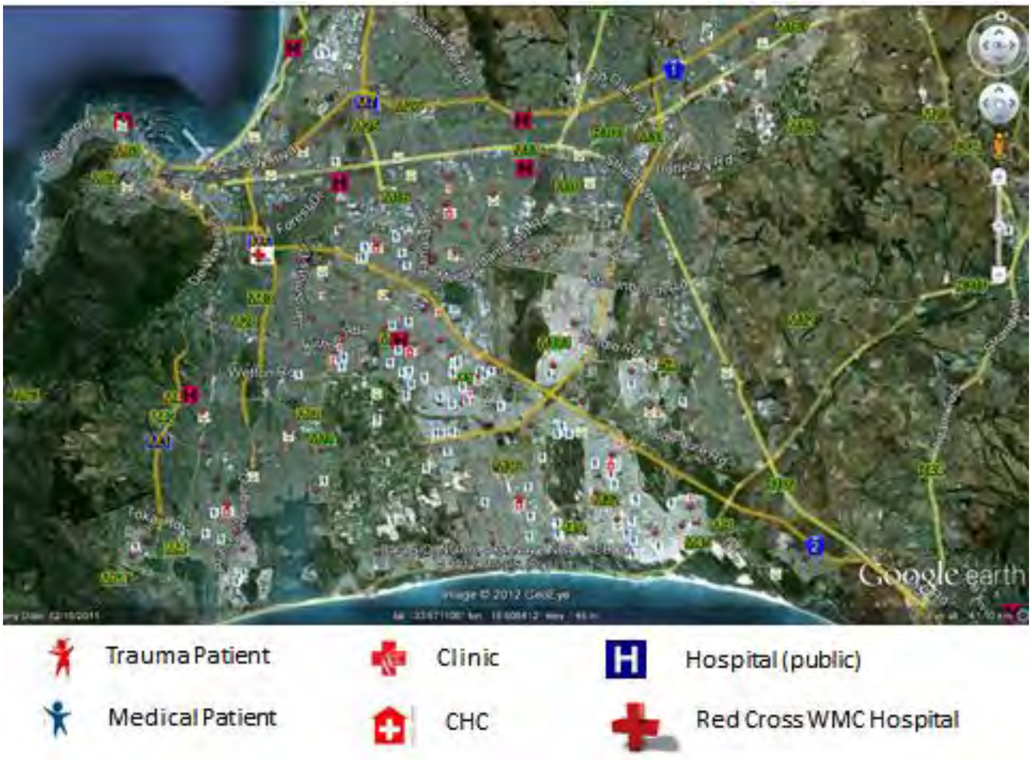


Fig 4 Example of detailed patient route mapping potential with GIS data

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VI. PROTOCOL: PATHWAYS TO CARE FOR CRITICALLY ILL CHILDREN

1. Background

The problem to be solved

Avoidable childhood death is relatively common in countries with limited economic resources. In South Africa, approximately 73 children per 1000 live births die before age 5years.[1] The most cost-effective way to prevent this high death rate is through primary prevention – vaccination, nutrition, sanitation, clean water and other public health interventions. However, secondary prevention is also important. WHO have estimated that 10-20% of children presenting to primary health care facilities are already sufficiently ill to benefit from onward referral.[2] A substantial number of these children will be critically ill and in danger of dying.[2 3] Good critical care in children is often life-saving[4] while poor critical care at any stage in the care pathway (at an accident scene, in primary care, during ambulance transport, in Emergency Centres, or in general paediatric wards) frequently leads to unnecessary death.

Paediatric critical care has been defined as: care of the child or infant with a life-threatening illness or injury from the time of presentation to the health services all the way through to resolution of that illness.[5]

Good critical care in children is often life-saving while poor critical care at any stage in the care pathway (at an accident scene, in primary care, during ambulance transport, in emergency centres, or in general paediatric wards) may lead to unnecessary death or morbidity.

Critical care in many resource-limited countries is often poor.[6] A review of hospitals in 7 countries found the quality of care was inadequate[3] with more than half the children under-treated or inappropriately managed; they listed lack of triage, inadequate assessment, inadequate drug supplies, poor knowledge of treatment guidelines and insufficient monitoring of sick children among key adverse factors. Others have found similar result. [7 8] Poor critical care of trauma victims is also a recognized as a common problem.[10] South Africa has inherited a highly inequitable system of care, with islands of excellence, such as the Paediatric Intensive Care Units (PICUs), amidst a system often providing less than optimal health care. There is a particular need to extend the influence of excellence to make services both better and more equitable. Continued pursuit of PICU excellence in isolation is not sufficient.

The research evidence

There is a significant body of research reporting the effectiveness of interventions to improve specific aspects of critical care. This research is not limited to hospital care. In the community, interventions have included training lay care workers to recognise and treat sepsis in neonates[11], training mothers to recognise and treat malaria[12], and training those likely to witness injuries, such as commercial drivers, to provide trauma care.[13] At the primary care level, the WHO initiative to improve effective triage through the IMCI programme was shown to be effective.[14-16] However, as the IMCI protocols were implemented there was increased recognition of the need to address practical barriers to onward referral[17] and to improve services at the hospital centres to which children were referred.[18 19]

The research gap

Although there is good evidence that changes in the care given to critically ill or injured children can have a profound impact on outcomes, and that many of these changes are inexpensive to implement, there is still little research evidence about the relative importance of each element of critical care. Give that resources to improve care are limited, where should they best be directed? What are the main causes of critical care failure? At what stage in the critical care pathway do things most often go wrong? What proportion of the deaths attributable to critical care failure might be prevented by addressing specific causes of care failure? We have not identified any previous research into the relative contribution of critical care system failures and successes along the whole pathway into intensive or emergency care which would provide evidence about the most effective changes to implement along the pathway.

We are aware of one existing initiative in South Africa (the Child Healthcare Problem Identification Programme - CHILD PIP) which is currently being introduced to hospitals throughout the country. However, the programme is not a formal research study and is based on non-expert audit of the medical records only of children who die. The proposed study seeks to augment this programme in five ways: 1) by applying formal research methodology with quality control of parameters such as completeness of ascertainment; 2) by collating evidence from all health care facilities involved in the critical care of each child; 3) by subjecting the evidence gathered to expert clinical review; 4) by eliciting accounts of the care provided from parents/caregivers; 5) by including all critically ill children, not just those who die.

Research methodology options

The ideal methodology to address the evidence gap would involve ascertaining all critically ill children in a defined geographical area. We assessed the feasibility of ascertaining events from all primary health centres and local hospitals in the Western Cape in the context of a previous study of the accuracy of mortality recording [20] and this did not appear to be logistically feasible. We therefore piloted the feasibility of ascertainment of cases at one of the two the central referral points for critically ill children, the Red Cross War Memorial Children's Hospital (RCWMCH). The strength of this approach is that it has the potential to obtain complete and timely information. The main weakness of this approach is that it will exclude critically ill children who die without reaching RCWMCH, thereby potentially underestimating the importance of failures of onward referral. We anticipate we will be able to overcome this weakness by including children who die at a sample of other health care facilities in the study.
We also piloted at RCWMCH the method of expert case review of which we have experience in Oxford.[21] This requires extraction and collation of data from various sources to produce a summary case-record which can be assessed in a time-efficient manner by an expert panel.

The confidential enquiry approach is essentially an independent expert audit of a series of cases which explicitly avoids attributing blame to individuals but seeks to identify modifiable system failure. In the UK, the perceived impact of the Confidential Enquiry into Maternal and Child Health in reducing maternal and perinatal deaths [22] has led to its recent extension to include all children.[23] The method does not involve recruitment of a control population due to the difficulty of ascertaining all children at-risk of becoming critically-ill means.

Work leading up to project - pilot study

The pilot study assessed the feasibility of ascertainment of critically ill children at RCWMCH: a strategy involving hot-pursuit of PICU admissions and of deaths in the Emergency centre proved feasible. Over a one month period we ascertained 44 emergency admissions to PICU and 4 deaths in the emergency centre. However, the hot-pursuit workload and impact on PICU staff was such that the research proposal below suggests restricting ascertainment to alternate weeks. Eliciting information from parents is important in defining the care pathway for each child and will be more straightforward in children admitted to PICU. The number of health facilities involved in the care pathway for each child prior to arrival as RCWMCH ranged from 1 to 5, with most children (61%) having been looked after at three or more facilities (counting ambulance transport as a facility). Records had to be obtained from each facility. Although collection of records from these facilities proved feasible, the paucity and ambiguity of some records often required direct questioning of staff by telephone to achieve clarification and this contact was far more likely to be successful if made as soon as possible after the event.

The expert review panel sought to identify failures of critical care which could be addressed. The most frequent "modifiable critical care events" involved inappropriate delay in seeking and provision of medical care, delays and inadequate monitoring during transport, inadequate triage in primary and emergency care, failure to initiate appropriate respiratory and circulatory support and failure to appropriately involve senior staff. Delay in admission to PICU was important in 9 out of the 44 cases, in addition to delays in first accessing care or in triage and onward referral in primary care and during ambulance transport. In the hospital setting, modifiable critical care incidents were more common in Emergency centres (63%) than in paediatric wards in local hospitals (46%) and regional hospitals (23%).

The purpose of the proposed study is to provide evidence to help improve the care of critically ill or injured children. It applies established "Confidential Enquiry" methodology to identify modifiable failures at each stage of care. It will underpin development and prioritisation of interventions (both education directed at individuals and modifications to the system of care) to minimise critical care failure in the future.

2. Research Plan

Aim

To identify preventable failures in the medical care of critically ill children ("modifiable critical care issues") at all stages of the care pathway, including care prior to hospital admission.

Design

Observational study of the medical care received by critically ill children through expert clinical review of medical records and interviews with parents or carers. Please see appendix for flow chart providing overview of the process.

Subjects and setting

At least 450 children aged <13 years who are admitted as emergencies to the PICU at the Red Cross War Memorial Children's Hospital (RCWMCH), or who die in the Emergency Centre of RCWMCH (this includes the trauma unit and the medical emergency unit). In addition we will include a sample of children dying in health facilities in the Cape Town Metropolitan West area which is the referral region for the RCWMCH during the study period. The sample will include deaths at all three hospitals in the area who care for paediatric emergencies, New Somerset Hospital, Victoria Hospital, False Bay Hospital, and the five 24 hour Community Health Centres (CHC) in the area who will see the vast majority of the critically ill paediatric emergencies: Guguletu CHC, Hanover Park CHC, Mitchells Plain CHC, Retreat CHC, Vanguard CHC.

Children who do not have a clear or relevant acute emergency pathway from their home to the healthcare services will be excluded from the study including: admissions for elective surgery, and any and all complications of this in the same hospital stay; neonates transferred direct from nursery/ maternity/ medical obstetric unit (MOU) without going home in interim; patients in a hospital ward (other than PICU) for more than 5 days immediately prior to PICU admission or death; patients where the primary reason for their PICU admission is not the same as the reason for their admission to RCWMCH; and death or dead on arrival (DOA) patients as a result of longstanding illness and/or a conscious decision to limit care prior to the present acute healthcare episode.

Objectives

1. To ascertain promptly and completely a representative sample of all emergency admissions to PICU, all deaths in the EC and a sample of deaths in the Metropolitan area.
2. To obtain as complete data as possible on the pathway of care of these children, from the onset of the illness episode until PICU admission or death, through abstraction and review of medical records and interviews with parents or carers.
3. To conduct an expert clinical review of these data in order to identify preventable failures in care contributing to unnecessary morbidity and mortality.
4. To assess the adequacy of the routine child mortality audit in South Africa (CHILD PIP) in identifying preventable failures in care.

Identification of cases

All PICU emergency admissions every second week for 12 months and all deaths in EC over 12 months (or until at least 450 patients are enrolled) will be identified by a designated research nurse who will visit the units each day to review the admission lists and talk to staff, and families. The severity of the child's illness on admission to PICU is already routinely recorded using the Paediatric Index of Mortality score. The decision to restrict identification of PICU admissions to every second week reflects experience from the pilot study; alternate week recruitment appeared to be more manageable, with more complete ascertainment and higher quality data extraction. The Emergency Services and where necessary other sources will be used to obtain numbers of child deaths in selected Metro West area healthcare facilities (3 hospitals and 5 community health centres).

Informed consent process

After identification of cases, consent will be taken from the caregiver to enter into this study (see attached consent forms and documentation). Consent will be taken by study personnel (in the family's home language) and not by general clinical staff. Every effort will be made to ensure that parents are given adequate time and privacy to make an informed decision. Every caregiver will be provided with a copy of the documentation and the consent form (including contact details for the investigators on the study). It will also be made clear that parents can withdraw from the study at any time if they so wish.

Please see appendix for further discussion regarding consent and interviews with parents.

Interviews with parents or carers

Personal interviews (in the home language of the family) will be conducted with the parents or caregivers of each child as close to admission/death as possible in order to elicit information about both the "path to care" for their child, and their own perceptions of the care (and quality of care) provided to the child and the family. Interviews will be semi-structured and conducted by interviewers trained in qualitative interviewing techniques. Parents will be asked to describe events chronologically, but will be encouraged to give their own account mainly through open-ended questioning (although closed questions will be used to achieve event clarity when necessary).

The interviewer will summarise the illness episode from the parent's perspective, including in particular any pre-contact lay care and difficulties, delays in accessing first contact care, and delays in medical assessment or onward referral. Interviews will be tape-recorded so that reports of potentially critical incidents can be reviewed and checked by the clinical review panel when appropriate.

(Please see addendum around concerns about the possible impact of the interview of the caregivers).

Collection of data from medical records

A key issue in obtaining high quality data in the pilot was promptness (hot-pursuit). As close to admission/death as possible, a designated research nurse will try to obtain copies of all clinical records relating to the episode of care leading to the critical event. Within RCWMCH, electronic data are available recording ambulance transfer and EC admissions. Other RCWMCH records held in paper form will be copied. Records of care prior to admission to RCWMCH will be sought from the referring hospital and any other hospital, community health care centre (CHC), primary care clinic or other health care worker involved in the episode of care leading to the admission. All relevant sections of the medical records at each stage will be copied and key staff in each location will be contacted by phone where necessary to clarify issues relating to modifiable critical care issues (see below) at each stage.

When all the available electronic and paper records for a specific child have been collected, a clinician will extract the information for analysis using a standardised data collection form (developed and refined in the pilot study, but currently undergoing ongoing development). The form allows direct entry of data onto an electronic database and focuses on:

i. Basic data comparable with CHILD PIP (admission details; family and demographic background; nutritional status; HIV/AIDs status; previous medical /developmental /social history).
ii. The information provided by the caregiver regarding the "pathway to care"
iii. Information on ambulance call and transfer.
iv. The care given and onward referral decisions made at each care contact step (i.e. home, ambulatory care, regional hospital, paediatric medical ward, Emergency centre, PICU).
v. Discharge information.
vi. For children who die, main cause of death and underlying conditions contributing to death.

vii. The clinician responsible for the data extraction will receive training prior to the data collection phase. The training will be assessed and will continue until there is full agreement between the training specialist and the data extraction clinician. During the study reliability will be established by repeating the data extraction of 10% of cases and examining the agreement.

Please see addendum regarding the development of relationships within the health services, and collaboration with the health services in this study

Summarising information on critical care

In extracting and summarising information on the care provided at each step of the care pathway, particular attention will be paid to eight key modifiable critical care issues: i) access to care and delay; ii) initial assessment or triage; iii) Airway maintenance, breathing and ventilation; iv) circulation, fluids and haemorrhage control; v) cervical spine protection; vi) hypoglycaemia; vii) medication errors; viii) Information will also be abstracted at each stage on senior staff involvement and any onward referral decisions or safety-net arrangements made.

Expert clinical review

Weekly clinical review meetings will be conducted by three critical care clinicians who will review the abstracted information on all children ascertained. The clinical review team will consist of two Cape Town clinicians specialized in critical care and/or emergency medicine and one similar international independent clinician who will participate in the panel electronically with full electronic copies of the cases. The purpose of including an external reviewer is to provide some external validation of the local judgements made.

Each meeting will review about 10 children. Each child's review will take place at the first meeting after ascertainment if possible, although a case may need to be considered at more than one meeting if there is delay in obtaining records from other centres on pre-RCWMCH admission care. The small number of cases which remain longer than 2 weeks in PICU will be re-reviewed on discharge or death when they occur. The information reviewed on each child will be: 1) the abstracted summary information described above (with copies of relevant sections of the medical record and x-rays where required); 2) a summary of relevant facts from the patient interviews. The same clinician will not be involved in a CHILD PIP mortality audit and the review of the death at the clinical review meeting.

A critical element of this review is the analysis of whether the care given in each setting is "appropriate". Considerable preliminary work is being done to establish appropriate standards of care at each level of the health system for a variety of conditions (see addendum). It is the intention of the research team to reach consensus with the Provincial authorities regarding what could be an acceptable standard of care. Currently there are teams working on fleshing out these definitions as a collaborative process.

Main outcomes

For each child, the review team will record:
1) the number and nature of modifiable critical care issues impacting on outcome at each stage of care (including failures in access, triage, transport, referral or assessment by experienced staff);
2) an overall statement on whether the death or severity of illness requiring PICU admission was avoidable,

partially avoidable, or unavoidable;
3) if the death or illness severity is considered partially or totally avoidable, a clear statement about what preventive action might be taken to minimise the risk of similar failures in future.

The main aggregate outcomes will therefore be:
1) the proportion of children suffering modifiable critical care incidents impacting on outcome and the frequency and nature of these incidents
2) the proportion of preventable deaths in emergency centres and in the PICU admissions

The key recommendation resulting from these outcomes will be the preventive actions that might be taken to minimise preventable deaths and PICU admissions. These recommendations will be illustrated by specific case-histories indicating examples of both good care and care failure.

Secondary outcomes

An important secondary outcome will be: i) the proportion of modifiable critical care incidents identified by this study which were identified by the CHILD PIP audit and ii) whether the factors identified by CHILD PIP differ from those identified by this study.

As children admitted to PICU will have a Paediatric Index of Mortality (PIM) score on arrival, as well as data on the length of stay or time to death, it will also be feasible to conduct a secondary analysis (in PICU admitted children) relating the extent of care failure (such as specific modifiable critical care incidents) with severity of illness on admission and length of stay or time of death.

Data analysis

The data analysis is observational and the main challenge is effectively distilling the key issues from 450 clinical review team summaries, with each child having a unique care pathway and suffering a variable number of delays and modifiable critical care incidents. On the basis of experience of handling similar data in the past, we anticipate handling the data in four ways:

5) a child-based analysis, developing a graphical method to display the different care pathways and timing of events
6) a child-based analysis, tabulating the proportion of children suffering modifiable critical care incidents.
7) a critical event based analysis, tabulating the frequency of different types of modifiable critical care incidents and their severity.
8) a theme-based categorical analysis, seeking to exemplify key issues from a limited number of case-histories of individual children.

Where appropriate, the quantifiable data will be presented using standard statistical methods (parametric or non-parametric), including confidence intervals to show the precision of any estimates or comparisons made.

To undertake the secondary validation analysis of the CHILD PIP mortality audits, we will assess the proportion of cases where there is agreement on care failure impacting on outcome. We will assess the extent to which the important modifiable factors identified from this study were identified by the CHILD-PIP analysis.

Description of risks and benefits

The study will elucidate the pathways for care of critically ill or injured children through the health system, and will enable the identification of critical points where intervention is likely to have most impact. This information is essential for further improvement of systems and training processes. The international collaboration in this project will upgrade the skills and capacity for health system analysis in South Africa. In addition the information collected will be published internationally with potential impact in many other countries throughout the world.

The proposed observational study presents minimal risks to the participants (NB. Additional material has been provided regarding the risks of interviews in this particular setting). The review of medical records does not present a risk to the children or their caregivers

Privacy and confidentiality / Data safety and monitoring

To ensure the privacy of participants and the confidentiality of data, paper-based records will be kept in a secure location and both paper- and computer-based records will only be accessible to personnel involved in the study
An electronic database will be established for the data. This will be web-based to provide access to the data to the international team on the study, but access to the data will be protected through passwords and privileges and changes or access to data will be tracked. Personnel will be required to sign statements agreeing to protect the security and confidentiality of identifiable information. Personal identifiers will be limited on data sheets (a study number will be provided to most data sheets). Recordings of interviews will be transcribed and then stored in a secure location to enable later further analysis should this be necessary.

Reimbursement for participation

Reimbursement for participation will not be provided to caregivers. However funds will be made available in order to help the parents/caregivers attend the hospital and facilitate interviews where necessary.

Systems review and intervention development

The outcomes of this study will only be important if they lead to changes in the care to remedy identified care failures and incorporate recognised strengths. In order to achieve such change, it is necessary to review the system of care which leads to failure and then to propose system interventions (which will usually involve changes in organisation as well as staff education). The MRC framework for the development and assessment of complex health service interventions provides a useful methodological guide which we will implement as far as is feasible in a resource-limited context.[24] With the funding allocated for the study we will aim to as a minimum reach stage 2 of the MRC process – identifying key system failures amenable to change, reviewing the theoretical and empirical base for possible interventions to achieve change, and seeking evidence about the likely local barriers to change (which will include lack of resources). If feasible, we will develop and seek funding for a pragmatic trial of a specified intervention to achieve change.

At the same time the study group has taken the following measures to try and establish "buy-in" from both the provincial service structures and the University teaching processes. An Advisory committee for this project has been established including the Dean of the Faculty of Health Sciences at the University of Cape Town (Professor Marian Jacobs) and the Deputy-Director of Health in the Western Cape (Dr Beth Engelbrecht). In the process of establishing the research project, the researchers will be working with teams established by the Emergency Medicine and Paediatric Provincial Co-ordinating committees, to establish both appropriate standards, and triage processes for the region. Every attempt will be made to contact all the institutional authorities who may be affected by the research, with an undertaking that we will provide feedback to them regarding all results of the study.

Study setting and feasibility

Ascertainment of subjects will take place in, and the study will be managed by, the RCWMCH - a local Tertiary level hospital for children up to 13 years of age. The Paediatric Intensive Care Unit (PICU) is a 22 bed unit which has both emergency and elective admissions for the Western Cape with over 1350 admission in 2008, 70% of which were emergency admissions. The EC is split into medical emergency and trauma, and has a combined census of approximately 48,000 patients a year. Sixty-nine children died in the EC during 2006.

Sample size and timing

In the 12 month study recruitment period we know we will ascertain 400 emergency admissions to PICU with ascertainment taking place every second week and 70 deaths in Emergency centre, and very small number (under 20 deaths) from outside healthcare facilities. This will provide reasonable precision in estimating the proportion of children suffering from critical care failures. For example, a proportion of 40% will be estimated with 95%CI of ± 4%. If the analysis is restricted to deaths (assuming a total of 120 deaths (70 in EC and 50 in PICU) the same proportion will be estimated with 95%CI of of ±9%. Deaths in other facilities outside of RCWMCH will further increase precision.

Research Team

This is a joint application from the University of Cape Town and the University of Oxford. The Cape Town investigators bring specific expertise in critical care (as well as local knowledge). The Oxford University investigators bring expertise in conducting health services research in resource-limited countries and in the Confidential Enquiry methodology. The Tropical Medicine Network and Department of Primary Health Care in Oxford both have an international reputation for research quality and expertise. The co-investigators have jointly designed the study; the data collection will take place in Cape Town with support from Oxford for the data analyses and writing-up.

3. Study impact

The study will elucidate the pathways for care of critically ill or injured children through the health system and the identification of critical points where intervention is likely to have most impact. This information is essential to allow improvement of systems, training and processes to reduce avoidable care failure with associated death and disability. This international collaborative project will upgrade the skills and capacity for health care system analysis in South Africa. It will enable health policy makers to focus on points of maximum benefit from interventions throughout the health care system and will have implications not only for health systems in South Africa, but also for health systems in similar contexts throughout the world. To maximise the likelihood that the findings will be translated into practice we are inviting the Deputy Director of Health for the Western Cape and the Dean of the Health Services Committee of Cape Town University to sit on the study Advisory Committee.

Timeline 30 months – see attached Gantt chart
Set up and training – 6 months
Data collection – 12 months
Data analysis and write and design of intervention – 12 months

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5. Appendix 1: Parent interviews

On review of the data from the pilot study, it became clear that it would be essential to have interviews with parents in order to have clarity about the exact events that took place during the "pathway to care". Records at institutions were frequently incomplete, and also did not provide critical information such as time of arrival, time seen, information given to parents *etc..* Thus it would be impossible to collect the relevant information without an interview with the parent or caregiver.

Personal interviews will be conducted with the parents or caregivers of each child as close to admission/death as possible in order to elicit information about both the "path to care" for their child, and their own perceptions of the care (and quality of care) provided to the child and the family. Generally these interviews will take place at the Red Cross War Memorial Children's Hospital at the convenience of the caregivers. Where necessary, the interviewers will go to meet the caregivers at an appropriate venue (may also include the home).

Interviews will be semi-structured (see attached datasheets) and conducted by interviewers trained in qualitative interviewing techniques. Parents will be asked to describe events chronologically, but will be encouraged to give their own account mainly through open-ended questioning (although closed questions will be used to achieve event clarity when necessary). The interviewer will summarise the illness episode from the parent's perspective, including in particular any pre-contact lay care and difficulties, delays in accessing first contact care, and delays in medical assessment or onward referral. Interviews will be tape-recorded so that reports of potentially critical incidents can be reviewed and checked by the clinical review panel when appropriate.

There has been major consideration of the fact that parents may find this process distressing, particularly if their child has died. However the following comments may be pertinent:

1) Relatively small numbers of children will actually die in the study (probably of the order of 10-15% of all admissions)
2) Routine care already provides considerable support to the parents in terms of:
   a) Clinician interviews and discussions with family to keep them informed of what is happening (or what has happened)
   b) A full time social worker is employed in the PICU to support families during and after admission of their child to the PICU. That social worker routinely sees families, and is involved in a follow-up process to feedback any outstanding results, and to check that families are coping following their bereavement.
   c) We have access to child psychiatry services who can be called upon to provide psychiatric support to the family
   d) A chaplaincy service operates in the hospital to support parents and families.
3) The staff doing the interviews will be trained to
   a) Treat the family members with great care and gentleness
   b) Ensure that no blame of any kind is attributed to the parents. It would be made clear that the research is simply to establish what happened (in the hope that this knowledge may facilitate future interventions to improve care).
   c) Use the interview as a form of "debriefing" during which parents would be given an opportunity to reflect on the process which they had gone through during their child's illness. It has been our experience that families are often relieved to be given an opportunity to relate what they have been through.
   d) Refer all questions regarding the current management or processes to the clinical team caring for the child and family (and facilitate this process)
   e) assure family members that comments will be confidential, but that if problems are identified, the team will ensure that investigations are initiated to try and ensure that problems in the future are minimized.
   f) If complaints or inadequacies of care are identified by parents, the research team will undertake to ensure that parents know the paths for lodging complaints, and that appropriate authorities are informed of the complaints from the families.
4) Parents and family will be informed during the consent process that they have every right to refuse, and indeed to withdraw consent at any time if they feel that the process is too traumatic.

There is a body of research around the death of children, and children with severe illness that has generally suggested that an interview process may be therapeutic, and is unlikely to be harmful (if carried out appropriately) (1-6).

Specific training for interviewers will be carried out by Mrs Nontobeko Jacobs, and Dr Alison Ward (UK) to ensure that they are appropriately prepared for these interviews.

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VII. CASE STUDY (73) : SZ

In order to give some insights to the depth and detail of information across the health system collected and analysed in the study, this is a summary (compiled from review of medical records from various facilities and EMS, and supplemented by information from caregiver interview conducted with the mother on the day following the child's admission to RCWMCH PICU) of an individual case from the Pathways to Care database, with timelines and outcome assessments and judgements as made by the expert panel.

Clinical Review of this Case:

Outcome: PICU Death
Primary Diagnosis: Septic shock (A41.9)
Secondary Diagnoses: Gastroenteritis (A09)
Poisoning (T65.9)
Metabolic acidosis (E87.2)

Timeline:

00h00 lift to clinic
00h30 +- arrival CHC
01h00 triage ? orange
02h15 dr's notes/ referral letter written
02h20 EMS incident P2
03h24 EMS dispatch
03h39 EMS arrival CHC
04h06 EMS depart CHC
04h37 EMS arrival RCWMCH
04h50 arrival RCWMCH (request for folder)
05h15 first assessment/ vitals
05h30 antibiotics IVI
06h12 CXR
6h30 review, PICU request
7h30 review
9h00 PICU admission

52 hours later:

12h45 DIED

Table 0-2 Vitals Signs for Each Step of Pathway

Facility	Pulse	BP	RR	Sats	FiO_2	Temp	GCS/ AVPU	CRT	HGT	Triage
Facility/Ward: CHC -	150	-	72	100	0.21	36.9	E4 V5 M6 (15)	4-5		Red
Ambulance Transfer:	100	-	32	89	0.4	-	E4 V5 M6 (15)	3-4		Red
Facility/Ward: RCWMCH Med EC	108	-	33	90	1	32.8	- (A)	3-4		Not recorded
Facility/Ward: RCWMCH - PICU	188	52/ 33	30 (v)	93	0.45	35.3	- (6)	>5		Not recorded

Pathway Details

1. Facility/Ward: CHC Level: CHC 24hr

Table 0-3 Standards for CHC

Standards Met		Standards Not Met
(1.3) General/Triage: Triage system in use		(1.1) General/Triage: Entry to facility - eyeball assessment [5min]
(2.2) Documentation: Doc time triage/first assessed		(1.2) General/Triage: Fast track for paeds
(2.3) Documentation: Doc time seen by HCP		(1.4) General/Triage: Triage RED - Mx by senior HCP [IMMED]
(2.7) Documentation: Doc HCW name		(1.5) General/Triage: Oxygen therapy Red in [5min]
(3.1) Gastro: Gastro HGT at intial assessm [IMMED]		(2.1) Documentation: Doc time arrival
(3.3) Gastro: Doc of signs&severity		(2.4) Documentation: Doc time Rx commenced
(3.4) Gastro: ID&Doc signs shock		(2.5) Documentation: Doc weight
(3.8) Gastro: Well nourished 20 ml/kg 1/2 DD IV		(2.6) Documentation: Doc time date assess/treat
(3.11) Gastro: HGT check&Mx if >=10%		(3.2) Gastro: Oxygen to Shocked Gastro [IMMED]
(3.12) Gastro - Shocked: IV or IO access		(3.10) Gastro: Oxygen admin if >=10%
(3.13) Gastro - Shocked: Unable site IV/IO then NG 30ml/kg/hr		(3.14) Gastro - Shocked: Shock Mx 20ml/kg NS repeated
(3.15) Gastro - Shocked: HGT check&Mx		(3.16) Gastro - Shocked: 2nd IV bolus&look cause
(8.1) Referral: Early EMS contact by PHC/ CHC level		(3.17) Gastro - Shocked: 3rd IV bolus&call help
(8.3) Referral: Referal letter contents		(3.18) Gastro - Shocked: Oxygen to all shocked
(8.4) Referral: Acceptance of any critical child by L2/3		(8.2) Referral: Referal communications for critical paeds

		(8.5) Referral: Facility handover to/from EMS
		(8.6) Referral: EMS communication to rec facility

Satisfaction with Treatment: Partial
Comments: delay especially around sleeping clerk
Satisfaction with Caregiver Explanation: No
Comments: nil given
Satisfaction with Caregiver Communication (language): Partial
Comments: through another HCW

Table 0-4 Modifiables for CHC

Modifiable Factor	Impact Category
FACILITY: Accessibility of Emergency Care area/ personnel (1.1)	Minor/Moderate impact
TRIAGE: Other - specify (2.3)	Minor/Moderate impact
MANAGEMENT: Resuscitation not done/ inadequate for shocked pt (4.2)	Major impact
MANAGEMENT: Ventilatory Issues (4.4)	Minor/Moderate impact
MANAGEMENT: Circulatory issues (4.5)	Minor/Moderate impact
MANAGEMENT: Antibiotic therapy (4.7)	Major impact
MANAGEMENT: Temperature Mx (4.9)	Minor/Moderate impact
CONSULTATION: No consultation to offsite specialists (5.3)	Minor/Moderate impact
REFERRAL: Communications with receiving facility (6.2)	Minor/Moderate impact
REFERRAL: Inappropriate referral mechanism (e.g.taxi/ private trnsprt) (6.4)	Not known
REFERRAL: Inadequate stabilization for transfer (6.5)	Major impact
REFERRAL: Ongoing monitoring/ management while awaiting transfer (6.6)	Minor/Moderate impact
REFERRAL: Other (6.8)	Minor/Moderate impact
COMMUNICATION: Explanation to caregiver (7.1)	Minor/Moderate impact
DOCUMENTATION: Missing/poorly documented information (10.2)	No impact

Comments from Reviewers:
REVIEWER 1:
1.1/ 2.3 Initial delay around opening file, and then unclear whether initially allocated a triage colour but considerable delay >10 min to being seen likely
4.2/ 6.5/ 6.6 The clinician seems to have assessed the baby well and made the right decisions but no follow through on resus and further fluid bolus/ reassessment the child was at the facility for another 2 hours almost - and clearly remained shocked.
4.4, 4.5, 4.7, 4.9 no oxygen given, poor IO access/ stabilization, no antibiotics given (even though suggests aspiration) and temperature management not considered although temp already 35.
5.3/ 6.2 Consultation to offsite/ receiving facility not considered, and referral letter written but not sent with baby
6.4 PFS should have done this transfer - unclear if they were contacted and unavailable hence ALS transfer
6.8 apparently no verbal or otherwise handover to EMS staff by CHC

Frustrating as the clinician seems to have made the correct assessment and had the intent to resus and manage well but no follow through/ re-e4valuation of obviously critical neonate.
REVIEWER 2:

where to start? so many problems here
why is the clerk asleep? delays in folder. delays in being assessed. delays in calling ems.
children <1 month are red on SATS
no reassessment. inadequate treatment *etc*.
REVIEWER 3:

Delays because of sleeping clerk. Inappropriate triage, triaged orange when clearly red. Good initial assessment, but then inadequate resuscitation, no administration of antibiotics, prolonged stay when needed immediate referral.

2. **Ambulance Transfer: Level: Inter-facility**

Table 0-5 Standards for EMS Transfer

Standards Met		Standards Not Met
(1.2) General: Arrival to Oxygen for RED [IMMED]		(1.1) General: P1 Calls EMS call-scene [15m]
(1.3) General: Triage system in use		(1.6) General: Referral communications for critical paeds
(1.4) General: EMS SATS RED treated by ALS		(1.7) General: EMS PFS for interfacility red transfer
(1.5) General: EMS Paeds approp resus equipment		(1.9) General: EMS communication to rec facility
(1.8) General: EMS ALS if no PFS		(3.5) EMS Gastro: Well nourished 20 ml/kg 1/2 DD IV
(1.10) General: EMS route child to closest approp facil		(3.8) EMS Gastro - Shocked: IV or IO access
(1.11) General: Acceptance of any critical child by L2/3		(3.9) EMS Gastro - Shocked: Shock Mx 20ml/kg NS repeated
(1.12) General: EMS handover rec/del facility		(3.11) EMS Gastro - Shocked: 2nd IV bolus&look cause
(2.1) EMS Documentation: Doc time call received		(3.12) EMS Gastro - Shocked: 3rd IV bolus&call help
(2.2) EMS Documentation: Doc time EMS team dispatched		
(2.3) EMS Documentation: Doc time arrival		
(2.4) EMS Documentation: Doc EMS time depart scene/ref facility		
(2.5) EMS Documentation: Doc EMS time destin facil		
(2.6) EMS Documentation: Doc EMS management		
(2.7) EMS Documentation: Doc EMS HCW name		
(3.1) EMS Gastro: Gastro HGT at intial assessm [IMMED]		
(3.2) EMS Gastro: Oxygen to Shocked Gastro [IMMED]		
(3.3) EMS Gastro: Doc of signs&severity		
(3.4) EMS Gastro: ID&Doc signs shock		
(3.6) EMS Gastro: Oxygen admin if>=10%		
(3.7) EMS Gastro: HGT check&Mx if>=10%		
(3.10) EMS Gastro - Shocked: HGT check&Mx		

Satisfaction with Treatment: Partial
Comments: delay in arrival but then happy with treatment when came
Satisfaction with Caregiver Explanation: No
Satisfaction with Caregiver Communication (language): No
Comments: by gestures only no shared language

Table 0-6 Modifiables for EMS Transfer

Modifiable Factor	Impact Category
EMS: Dispatch time delay (8.4)	Minor/Moderate impact
EMS: Inappropriate vehicle/ crew/ equipment (8.7)	Not known
MANAGEMENT: Circulatory issues (4.5)	Minor/Moderate impact
MANAGEMENT: Temperature Mx (4.9)	Minor/Moderate impact
EMS: Inadequate stabilization for transfer (8.8)	Major impact
EMS: Inadequate assessment before transfer (8.9)	Minor/Moderate impact

REVIEWER Comments:

REVIEWER 1:

8.4 overall response time 79 minutes for P1 (and it seems ALS if not PFS requested)
8.7/ 4.5/ 4.9 PFS perhaps better equipped/ skilled (esp for temp regualtion and IV access which were both a problem)
8.8/ 8.9 Clearly not stable at onset and no obvious attempts to bolus/ stabilize although difficult when already seen and "managed" bya doctor perhaps. Lack of a handover also problematic.

REVIEWER 2:

time to respond
p2 not p1
poor care
no handover
tews 2 - really??

REVIEWER 3:

Prioritization of case seems inappropriate. Significant drop in temperature while in transit. No vascular access, no obvious evidence of attempt at intra-osseous access. Clearly unstable to start with. The dropping heart rate was problematic and apparently not noted at all

3. Facility/Ward: RCWMCH - Med EC   Level: Red Cross Hospital Emergency Centre

Table 0-7 Standards for RCWMCH EC

Standards Met		Standards Not Met
(1.1) General/Triage: Entry to facility - eyeball assessment [5min]		(1.6) General/Triage: Triage ORANGE - Mx [10min]
(1.3) General/Triage: Triage system in use		(2.2) Documentation: Doc time triage/first assessed
(2.1) Documentation: Doc time arrival		(2.3) Documentation: Doc time seen by HCP
(2.4) Documentation: Doc time Rx commenced		(5.8) Fever/Septic Shock: Doc evidence meningitis
(2.5) Documentation: Doc weight		(9.3) ICU Referral: ICU request (non-ventil) to ICU bed [2h]
(2.6) Documentation: Doc time date assess/treat		(9.6) ICU Referral: Monitoring Ventil/ Crit Pt: nurse ratio 1:1
(2.7) Documentation: Doc HCW name		(9.7) ICU Referral: Monitoring of vitals every 15 m
(3.1) Gastro: Gastro HGT at intial assessm [IMMED]		(9.8) ICU Referral: Monitor/ventil equipm outside ICU
(3.2) Gastro: Oxygen to Shocked Gastro [IMMED]		
(3.3) Gastro: Doc of signs&severity		
(3.4) Gastro: ID&Doc signs shock		
(3.8) Gastro: Well nourished 20 ml/kg 1/2 DD IV		
(3.10) Gastro: Oxygen admin if >=10%		
(3.11) Gastro: HGT check&Mx if >=10%		
(3.12) Gastro - Shocked: IV or IO access		
(3.14) Gastro - Shocked: Shock Mx 20ml/kg NS repeated		
(3.15) Gastro - Shocked: HGT check&Mx		
(3.16) Gastro - Shocked: 2nd IV bolus&look cause		
(3.17) Gastro - Shocked: 3rd IV bolus&call help		
(3.18) Gastro - Shocked: Oxygen to all shocked		
(5.4) Fever/Septic Shock: Septic Shock triage-IV bolus [10m]		
(5.5) Fever/Septic Shock: Septic Shock triage-Abics [30m]		
(5.6) Fever/Septic Shock: Temperature documented at triage		
(5.7) Fever/Septic Shock: Urine testing (if<3/12 or no obv cause)		
(5.9) Fever/Septic Shock: Early recogn septic shock		
(5.10) Fever/Septic Shock: ID&Doc SHOCK		
(5.11) Fever/Septic Shock: IV IO access early		

(5.12) Fever/Septic Shock: HGT Mx (check and treat as approp)		
(5.13) Fever/Septic Shock: Approp Abic given IV/IM		
(5.14) Fever/Septic Shock: Inotropes/ vasopressors if unresponsive		
(5.15) Fever/Septic Shock: Referral of s/shock to appropr facility(PICU)		
(9.1) ICU Referral: ICU request to ICU assessment [1 hour]		

Satisfaction with Treatment: Partial
Comments: mother not allowed to be present throughout resus - wanted to be there
Satisfaction with Caregiver Explanation: Yes
Satisfaction with Caregiver Communication (language): Partial
Comments: through translator
Exemplary Issues: particularly impressed with a bearded doctor who made a lot of effort to explain to mother

Table 0-8 Modifiables for RCWMCH EC

Modifiable Factor	Impact Category
TRIAGE: Inadequate assessment at triage (2.1)	Not known
REFERRAL: Ongoing monitoring/ management while awaiting transfer (6.6)	Minor/Moderate impact
Referral Delay (6.7)	Minor/Moderate impact
DOCUMENTATION: Missing date/times (10.1)	No impact

REVIEWER Comments:
REVIEWER 1:

Treatment seems rapid and appropriate, even though the child was not in a great state when arriving at PICU 5 hours later - perhaps more to do with the childs condition/ pathology than the treatment?
2.1 Unclear whether this child was formally triaged and what the delay was to being seen - likely 15-20 minutes
6.6 monitoring (or at least documentation thereof) poor and irregular and no BP ever recorded in 5 hour stay
REVIEWER 2:

notes poor
delays
care seems appropriate
REVIEWER 3:

Gap of > 1hour between time of arrival from ambulance and time when apparently first seen. Hypothermic (dealt with), shocked (given IV fluids, but over a 2 hour period no improvement in overall condition of child), antibiotics given. 2 hour delay before consultation with PICU even though this child was clearly a candidate for immediate PICU admission. Ended up spending 5 hours with limited monitoring, significant problems that were not addressed, no evidence of senior / consultant input over this period.

4. Combined Modifiable Factors

Table 0-9 Combined Modifiable Factors

Facility	Modifiable Factors	Impact
Facility/Ward: CHC	FACILITY: Accessibility of Emergency Care area/ personnel (1.1)	Minor/Moderate impact
	TRIAGE: Other - specify (2.3)	Minor/Moderate impact
	MANAGEMENT: Resuscitation not done/ inadequate for shocked pt (4.2)	Major impact
	MANAGEMENT: Ventilatory Issues (4.4)	Minor/Moderate impact
	MANAGEMENT: Circulatory issues (4.5)	Minor/Moderate impact
	MANAGEMENT: Antibiotic therapy (4.7)	Major impact
	MANAGEMENT: Temperature Mx (4.9)	Minor/Moderate impact
	CONSULTATION: No consultation to offsite specialists (5.3)	Minor/Moderate impact
	REFERRAL: Communications with receiving facility (6.2)	Minor/Moderate impact
	REFERRAL: Inappropriate referral mechanism (e.g.taxi/ private trnsprt) (6.4)	Not known
	REFERRAL: Inadequate stabilization for transfer (6.5)	Major impact
	REFERRAL: Ongoing monitoring/ management while awaiting transfer (6.6)	Minor/Moderate impact
	REFERRAL: Other (6.8)	Minor/Moderate impact
	COMMUNICATION: Explanation to caregiver (7.1)	Minor/Moderate impact
	DOCUMENTATION: Missing/poorly documented information (10.2)	No impact
Ambulance Transfer:	EMS: Dispatch time delay (8.4)	Minor/Moderate impact
	EMS: Inappropriate vehicle/ crew/ equipment (8.7)	Not known
	MANAGEMENT: Circulatory issues (4.5)	Minor/Moderate impact

	MANAGEMENT: Temperature Mx (4.9)	Minor/Moderate impact
	EMS: Inadequate stabilization for transfer (8.8)	Major impact
	EMS: Inadequate assessment before transfer (8.9)	Minor/Moderate impact
Facility/Ward: RCWMCH - Med EC	TRIAGE: Inadequate assessment at triage (2.1)	Not known
	REFERRAL: Ongoing monitoring/ management while awaiting transfer (6.6)	Minor/Moderate impact
	Referral Delay (6.7)	Minor/Moderate impact
	DOCUMENTATION: Missing date/times (10.1)	No impact

5. Reviewer Assessment of Care

Table 0-10 Reviewer Assesment: Facility & EMS

Facility	Consensus Grade
Facility/Ward: CHC	Poor (all reviewers)
Ambulance Transfer:	Poor (all reviewers)
Facility/Ward: RCWMCH Med EC	Fair (R1, R4 Fair; R2, R3 Poor)

Table 0-11 Reviewer Assessment

Aspect	Reviewer Grade/Assessment	Consensus Grade/ Assesment
Global Assessment	R1: Fair, R2: Poor, R3: Poor, R4: Poor	Poor
Avoidability of ICU	R1: Not avoidable, R2: Not avoidable, R3: Not avoidable, R4: Not avoidable	Not avoidable
Avoidability of Severity	R1: Potentially avoidable, R2: Potentially avoidable, R3: Potentially avoidable, R4: Potentially avoidable	Potentially avoidable
Significant Outside Issues	R1: Possibly, R2: Yes, R3: Possibly, R4: Yes	Yes

6. System ISSUES/ Remedial Actions

REVIEWER 1:

Expert Comment on System Issues: Traditional medications allegedly given??

Remedial Action:

CHC - staffing/ system issues with "sleeping" clerk as well as mother having to get folder before being helped with sick baby

CHC - training/ protocol management shock/ shocked gastro and antibiotics

CHC - use of PFS, handover to EMS

EMS - delays ++, assesment and resus of child even if referring institution has apparently assessed and managed but child unstable

RCWMCH triage, documenting times, PICU delay in bed availability

REVIEWER 2:

Expert Comment on System Issues: traditional health system needs scrutiny and controls

Remedial Action: within the pathway, so many problems! night time care at CHCs remains a huge challenge

REVIEWER 3:

Expert Comment on System Issues: This child had lost a huge amount of weight on admission, not sure how well mother was warned of "danger signs". Not really a "fast-track" for sick small infants

Remedial Action: Need review of care of sick small infants

The response times and appropriateness of ambulance response team selection needs review

significant delays between arrival and admission to PICU

7. Summary & Research Questions from this case

This case is a true narrative, pieced together from multiple sources by the Pathways to Care Research Project. The case offers numerous in depth tiers of information relating to the emergency care of an individual child across the health system in Cape Town. Of note there are many cases with a happy ending and children restored to health and discharged home against the odds, but sadly there are too many cases where cumulative errors and omissions of the system result in a poor outcome as seems likely in this case. So many issues beg further analysis, understanding and ultimately interventions to change and improve the system. Some of the issues from this narrative would be:

- **Home Care** – what knowledge did the mother have of danger signs and how to deal with them in her new-born baby? Breastfeeding? Home care? Oral rehydration?
- **Access to care** – Why did this mother wait for the child to get so ill before seeking help? Why didn't she call for an ambulance? Are the ambulances really so slow? Why didn't she know the emergency number? Was the CHC she went to the closest/ only/ best facility to help with her sick child?
- **Access to facility** – Why is the medically untrained security guard the key to entry to a facility? How does a caregiver know how and where to go within a facility with a desperately sick child? Folders are required first from a sleepy clerk while child waits and deteriorates? Triage – is it done and does it work? Delays and barriers all the way – the mother has to really persist and beg for help - even though she is in a health facility with a desperately ill child.
- **Primary Health Care** – Who was the first health care practitioner to see this baby? Did they examine her and realize how sick she was? If so why didn't they start the basic emergency nursing care this child clearly needed? Delay to the doctor – was he/ she seeing an equally sick patient who couldn't wait? Was there no other practitioner available to help at that hour? Why the delays? Or were the delays only in documenting the management retrospectively perhaps? The doctor seems to have recognized a critically ill baby- but was unable/ unwilling to spend the time and properly resuscitate this child – why? The child received some (minimal) initial resuscitation but no follow up or monitoring for several hours while she continued to deteriorate – why? Was there a senior doctor to help/ offer advice? Was there a phone call to the receiving hospital to inform them/ discuss/ get advice? Is this the practice? No antibiotics for a shocked and potentially septic neonate – appropriate?
- **Communication -** What was the mother told – and did she understand it?
- **Documentation -** Doctor's documentation was scant and not up to medico legal scrutiny – why?
- **EMS Call out/ Dispatch**– Who called the ambulance and when? What information was relayed? What acuity/ severity/ priority was communicated and facilitated the dispatch of an ambulance team? Why the delay of several hours?
- **EMS Management -** EMS records reflect a child seemingly abandoned in a corner with little care in place – was this the reality? Why no handover by the staff of a critical baby? Or demand for intervention and handover by the ambulance crew? Was the ambulance crew trained and equipped adequately for this child? Was the care en-route appropriate? Was it appropriate to "scoop and run" for the hospital with this child? Or would more aggressive "stay and play" resuscitation prior to the transfer have been appropriate? What was the mother told, where was she en route and what did she understand?

- **Children's Hospital** – Was the child routed directly and appropriately to the resuscitation bay? Was triage performed – if so by whom and where documented? Initial resuscitation – was it as good as the documentation suggests? What happened for the next few hours as little documented? Were they swamped with patients? Or monitoring without documenting specifically? What was the communication with PICU – did they accept/ assess the patient? Why the delay to PICU with what appears to be minimal care in the interim? Communication between doctors/ shifts/ disciplines? What was the mother told and what did she understand?
- **What in each step could have improved the outcome and changed the pathway?**
- **Was the care in each step appropriate** for the context/ level of care/ resources available in each step? And if not what could change this?
- **Was the outcome (death) avoidable?**

By collecting and piecing together the information gleaned from interviewing the mother of this child, collecting the CHC and hospital records, as well as the ambulance records for this child, and then conducting an expert clinical review of the case, we were able to assess the care received by this child at every step in the pathway, to identify, quantify and grade the omissions and errors within each step, and explore the overall care of such a child. We were able to further extrapolate and generalize this by scrutinising another 281 critically ill and injured children over a one year period to reveal the true nature of the pathways to care in a patient centred and longitudinal fashion novel to research in this area.
This case may not represent a fair representation of the "typical" story of the healthcare of a child in Cape Town – the majority do not get so sick due to good preventative health care; or when they are sick present early and are treated successfully by primary health care services before they require onward referral; or for those that are sufficiently ill for onward referral many are thankfully better managed and discharged home after their episode to grow to productive adulthood. However, the avenue to intensive care is a necessary one even in the most developed society and examining the worst case scenario – in this case those who are critically ill or injured such that they require intensive care or die on their way to care, is key to saving the lives of the sickest children.

VIII. Caregiver Interview Schedule

DEMOGRAPHIC DATA:

1. Name of Child
2. Date of Birth
3. Relation with Interviewee
4. Address (where child resides)
5. Name of Mother
   - Age
   - Marital Status
   - Language
   - Highest educational level
   - Employment Status
   - Contact no.
   - Contact Employer (if employed)
6. Biological Father
   - Age
   - Marital Status
   - Address (if different from mother and child)
   - Language
   - Highest educational level
   - Employment Status
   - Contact no.
   - Contact Employer (if employed)
7. Primary care giver (if not biological mother)
   - Name
   - Age
   - Address
   - Contact no.
   - Marital Status
   - Relation to child

SOCIAL DATA

1. Name of Residential Area
2. Description of Area/locality: Informal Formal Other, specify
3. Type of Dwelling: Formal Informal Traditional Other, specify.
4. Construction of Home
5. Number of Rooms
6. Amenities (water/ electr/ sewage/ *etc.*)
7. Assets
8. Nearest Health Facility:
   - Name of Facility
   - Distance from your House
   - Hours of Service at Facility

Mode of transport to nearest clinic:

Walk …Taxi ….Train …Private Car …Other, specify Cost/single trip .

9. Nearest 24hr service Health Facility (If same as 4 above, skip and go to 6)

Name of Health Facility

Distance from Home

Mode of transport to 24hr health Facility:

Walk …Taxi … Train … … Private Car ….Other, specify Cost/single trip ….

10. Ambulance services:

What do you do if:

If your child is very sick at home?

Your child is involved in an accident?

Why do you not call an ambulance?

- Do not know the telephone number
- Do not have money to pay for ambulance
- It does not come into my community
- Other, specify

11. Financial Support:

Household Income

Receiving any Grant: Yes … No ….if yes, type of grant

Is Father maintaining the child: Yes ……. No ….

If Not, is he paying Child Maintenance: Yes No

12. Family Data:

How many children are currently directly dependant on you? …

Gender of each child Multiple Birth: Y/N Age of child Alive: Y/N

Have any children died while under your care?

CARE GIVEN AT EACH FACILITY:

1. Can you tell me what happened to your child from the onset of the illness i.e. the first signs of illness in your child?

1.1.1.What were the signs?

1.1.2.How long ago did these signs begin? (note date/time)

1.1.3. When did you decide to seek medical help?

1.1.4.What made you decide to seek medical help? (note date/time)

1.1.5.Before seeking medical help, did your child receive any treatment for this illness? If so:

1.1.5.1. Can you please describe the treatment?.

1.1.5.2. Who provided the treatment (caregiver, family, traditional healer, chemist, other – note name of helper and facility) .

1.1.5.3. In your opinion, was the treatment helpful?

If the child is SICK, ask question a) MEDICAL below:
If the child has been injured, accident etc., skip and ask b)TRAUMA below:

a) MEDICAL CASE

2. Tell me about all the steps that you followed in seeking care for your child, distance travelled, mode of transport and costs, time of arrival at each facility, waiting time at each facility, when were you attended to and your perception of care provided.
   2.1. Name of Facility visited
   2.2. Time you left home …Mode of Transport Cost/single trip …
   2.3. Time of Arrival at facility …
   2.4. What was the first thing that was done upon entering the facility (checking of vital signs/ triage)
   2.5. Was there a separate queue for children and adults? Yes No
   2.6. Time of being attended by a health care provider
   2.7. <u>In the case of Gastro:</u>
      2.7.1. Was the child given any oral hydration? Yes… No…For how long: ….
      2.7.2. Was a drip put up? Yes . No If yes, when and where who put it up? Doctor …. Nurse …
   2.8. <u>In the case of ASTHMA or Respiratory Distress:</u>
      2.8.1. Was the child nebulised? Yes .No if yes, when …
      2.8.2. Was the process repeated? Yes … No
   2.9. <u>In the case of FEVER or SEPTIC SHOCK:</u>
      2.9.1. Was the child's urine tested? Yes . No … at what time …
      2.9.2. Were you told why the urine is being tested? Yes No .
   2.10. <u>In the case of Convulsions</u>
      2.10.1. How frequent were the convulsions whilst you were still at home? …
      2.10.2. If you called an ambulance, what was done when the ambulance arrived . If not, on arrival at the facility?
   2.11. Do you feel that you were attended quite quickly: Yes… No and why do you say so?
   2.12. What was the outcome
   2.13. What were you told about your child's illness
   2.14. Who explained the child's illness to you?
   2.15. In your opinion, could the medical care provided to your child have been improved? If so, how?.

b) **TRAUMA PATIENT:** (Scene of accident)

2. What time did the accident/injury occur? .
   2.3. What was the first assistance you received?
   2.4. Who was with you at the time ….
   2.5. Was any first aid care done? Yes… No if yes, by whom?
      2.5.1.1. What was done ….
   2.6. Was an ambulance called? Yes No if yes, by whom?
   2.7. When did the ambulance arrive? How long was the waiting? Short/long. Estimate period of waiting …
   2.8. How long did it take you to get to the nearest Health Care Facility from the scene of the accident?
   2.9. What care was given to your child in the ambulance, on the way to the nearest health facility?
   2.10. What injuries did the child sustain? …
   2.11. Was the extent of the injuries explained to you at the scene of the accident?

2.12. What was the level of consciousness of the child at the scene of accident?
2.12.1.1.1. Alert React to voice React to pain Unresponsive .
2.13. Were you (parent/carer) allowed to stay with the child throughout the time? Yes No
2.14. Name of Facility visited …
2.15. Time you left accident scene …Mode of Transport Cost/single trip …
2.16. Time of Arrival at Health facility …
2.17. Who directed you about where to go in the facility?
2.18. What was the first thing that was done upon entering the facility?
2.18.1.1.1.1. (checking of vital signs and triage)
2.19. Was there a separate queue for children and adults?
2.19.1.1.1. Yes No
2.20. Time of being attended by a health care provider
2.21. Do you feel that you were attended quite quickly: Yes… No…. and why do you say so?
2.22. What was the outcome ?
2.23. What were you told about your child's illness
2.24. Who explained the child's illness to you?
2.25. In your opinion, could the medical care provided to your child have been improved?
2.25.1.1.1.1. If so, how?.

3. Please tell me about anything you feel is important that was not covered in the interview…

INTERVIEW FEEDBACK

1. How stressful did you find taking part in this interview? (tick one)
   Not at all A little Somewhat Very stressful
2. How did you find the length of the interview?
   About all right Too long Too short
3. Would you be prepared to participate in this type of interview again?
   Yes No

IX. Quantitative Data Collected for Each Case

1. Patient Demographics
   - Name
   - Date of Birth
   - Gender
   - PICU Admission Diagnosis
   - Hospital Number
   - PICU Number
   - Medical/ trauma
   - Home address
2. Antenatal/ Developmental History
   - Birth Weight (& binned)
   - Antenatal booking status
   - Mode delivery at birth
   - Gestational Age at Birth
   - Obstetric risk factors
   - Current weight
   - Current height
   - Current head circumference
3. Social
   - Mother's status (alive/ dead/ sick)
   - Father's status (alive/ dead/ sick)
   - Primary Caregiver (M/ F/ grandparent/ *etc.*)
   - Where is child living
   - Nutritions (breast/ formula/ meals)
   - Nutritional Status
   - Feeding in first 6 months
4. HIV/ AIDS Status
   - Status (lab neg/ pos/ inf/ exposed)
   - PMCT
   - ARV
   - ARV mother
   - ARV father
5. Previous Medial History
   - Immunization up to date?
   - Congential anomaly? Details..
   - Convulsions?
   - Recent surgery?
   - Admission in last 3 months. (ICD 10)
   - Seen in PHC facility in last 3 months?
6. Outcome
   - Final status (alive/ died PICU/ death prior PICU)
   - Primary Diagnosis (ICD10)
   - Secondary Diagnoses (ICD10)
   - PIM2 Score
   - HIV status
   - HIV Clinical Stage
7. Length of Stay
   - RCWMCH Admission Date
   - PICU Admission Date
   - PICU Discharge Date
   - Hospital Discharge Date or Death Date
   - Transferred to Ward:
8. Outcome
   - Discharge Home?
   - 30 day outcome. Details…
   - Records of referral/ follow up appointment
9. Facility
   - Name of Facility/ Ward
   - Level of Facility
   - Medical/ trauma
   - Transferring Facility/ place. Details…
10. Background
    - Date illness started
    - Admission Diagnosis
    - Previous treatment. Details..
11. Prior Consultations at this facility (in last month)
    - Date
    - Diagnosis
    - Interventions
    - Follow up

12. Arrival/ Admission
- Transport to facility
- Arrival Date & time
- For Operating Theatre only:
  - Start & End time anaesthetic/ surgery
- Qualifications of first nurse assessing
- Date/ time seen by nurse
- Qualifications of first doctor assessing
- Date/ time seen by doctor
- Discussed/ seen by consultant?

13. Initial Assessment
- Pulse Oximetry
- Inspired Oxygen Concentration FiO_2
- Heart Rate
- Blood Pressure
- Respiratory rate
- Temperature
- Glasgow Coma Scale / AVPU
- Haemo Glucose Test
- Haemoglobin
- Weight
- Capillary Refill Time
- SATS Triage Colour

14. Interventions
- Airway
- Respiratory Support
- FiO2
- Vascular Access
- IV Fluids given/ type
- Inotropes
- Blood Transfused
- FOR TRAUMA ONLY:
  - Intercostal Drain
  - Cervical Spine Protection
  - Spine Board
  - Splinting/ Backslab to fracture
- Glucose given?
- Drugs given:
- Lab Investigations:
- Urine test
- Xray:
- CT Scan… Time

15. Progress/ Referral/ Discharge
- Admission overnight? Daily Details: Overall condition; Abnormalities; Issues
- Critical Event Details…
- Referal/ Discharge Details/ Date/Time
- Transport out
- Quality of Records

16. EMS
- Referring Facility
- Receiving Facility
- Background Diagnosis/ Prior Treatment

17. EMS Crew & Timing
- Date
- EMS level (home/ scene/ flt/ PFS)
- EMS type (primary/ secondary)
- Med/ Trauma
- Voucher Number/ Incident Number/ Vehicle Number
- Ambulance Group
- Priority Status
- Paediatric Flying Squad Vehicle?
- Incident date/ time
- Dispatch date/ time
- Arrival Scene date/ time
- Departure date/ time
- Arrival Destination date/ time
- Crew Qualifications

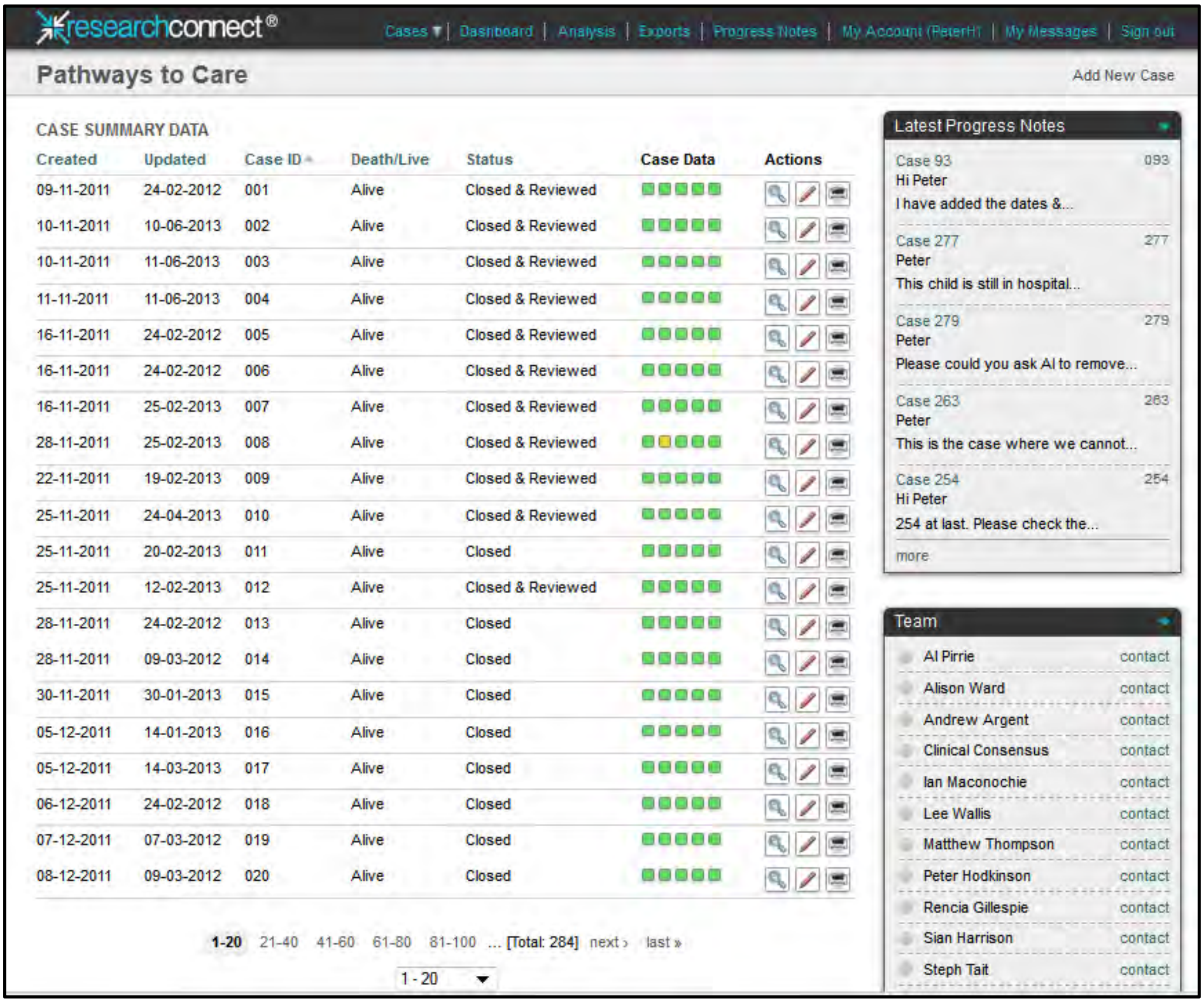
18. Initial Assessment
- Pulse Oximetry
- Inspired Oxygen Concentration FiO_2
- Heart Rate
- Blood Pressure
- Respiratory rate
- Temperature
- Glasgow Coma Scale / AVPU
- Haemo Glucose Test
- Haemoglobin
- Capillary Refill Time
- Initial SATS Triage Colour

19. Interventions
- Airway
- Respiratory Support
- FiO2
- Vascular Access
- IV Fluids given/ type
- Inotropes
- FOR TRAUMA ONLY:
    - Intercostal Drain
    - Cervical Spine Protection
    - Spine Board
    - Splinting/ Backslab to fracture
- Glucose given?
- Drugs given:

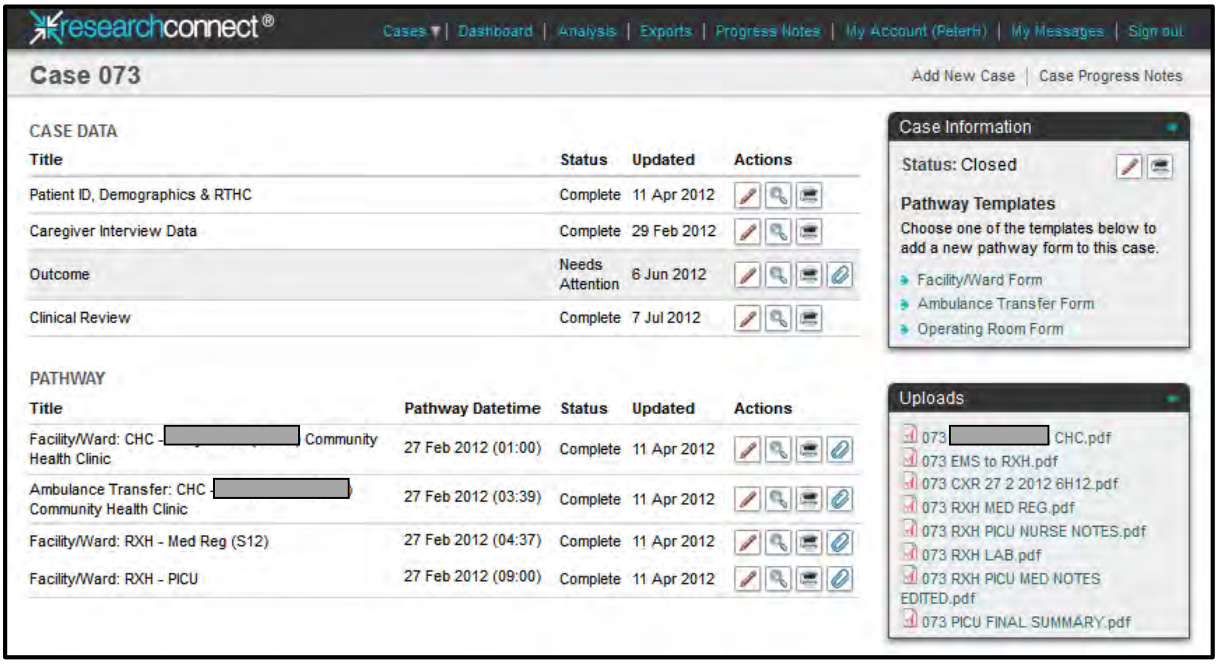
20. EMS Disposal
- Handover by (qualification)
- Handover to (qualification)
- Records of Referral

X. Screenshots of Online Database

Screenshot 1 "Home" page of the Pathways to Care database, showing each case, the status of each case and its review status. 294
Screenshot 2 - Individual case "pathway" and data, as well as PDF images of the medical records for each step of the pathway on the bottom right. 295
Screenshot 3 - Clinical review form in the database, showing the Vital Signs of a patient, populated from the data in each facility/ EMS form 295
Screenshot 4 Free text comments by each reviewer with respect to an individual health facility within a case 296
Screenshot 5 Graded Standards Applicable to a Facility 297
Screenshot 6 - Aggregated modifiable factors and their grading's for a case 298
Screenshot 7 - Clinical Review Form, showing assessments of each reviewer (this data only available retrospectively to co-ordinators - not to blinded reviewers) 299



Screenshot 1 "Home" page of the Pathways to Care database, showing each case, the status of each case and its review status.



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Cases ▾ | Dashboard | Analysis | Exports | Progress Notes | My Account (PeterH) | My Messages | Sign out

Case 073

Add New Case | Case Progress Notes

CASE DATA

Title	Status	Updated	Actions
Patient ID, Demographics & RTHC	Complete	11 Apr 2012	
Caregiver Interview Data	Complete	29 Feb 2012	
Outcome	Needs Attention	6 Jun 2012	
Clinical Review	Complete	7 Jul 2012	

PATHWAY

Title	Pathway Datetime	Status	Updated	Actions
Facility/Ward: CHC - [redacted] Community Health Clinic	27 Feb 2012 (01:00)	Complete	11 Apr 2012	
Ambulance Transfer: CHC - [redacted] Community Health Clinic	27 Feb 2012 (03:39)	Complete	11 Apr 2012	
Facility/Ward: RXH - Med Reg (S12)	27 Feb 2012 (04:37)	Complete	11 Apr 2012	
Facility/Ward: RXH - PICU	27 Feb 2012 (09:00)	Complete	11 Apr 2012	

Case Information

Status: Closed

Pathway Templates

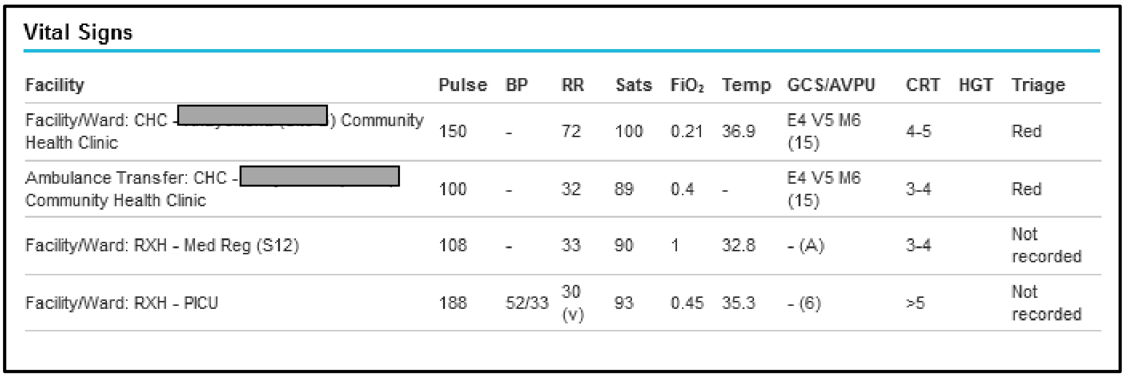
Choose one of the templates below to add a new pathway form to this case.

- Facility/Ward Form
- Ambulance Transfer Form
- Operating Room Form

Uploads

- 073 [redacted] CHC.pdf
- 073 EMS to RXH.pdf
- 073 CXR 27 2 2012 6H12.pdf
- 073 RXH MED REG.pdf
- 073 RXH PICU NURSE NOTES.pdf
- 073 RXH LAB.pdf
- 073 RXH PICU MED NOTES EDITED.pdf
- 073 PICU FINAL SUMMARY.pdf

Screenshot 2 - Individual case "pathway" and data, as well as pdf images of the medical records for each step of the pathway on the bottom right.



Vital Signs

Facility	Pulse	BP	RR	Sats	FiO_2	Temp	GCS/AVPU	CRT	HGT	Triage
Facility/Ward: CHC - [redacted]) Community Health Clinic	150	-	72	100	0.21	36.9	E4 V5 M6 (15)	4-5		Red
Ambulance Transfer: CHC - [redacted] Community Health Clinic	100	-	32	89	0.4	-	E4 V5 M6 (15)	3-4		Red
Facility/Ward: RXH - Med Reg (S12)	108	-	33	90	1	32.8	- (A)	3-4		Not recorded
Facility/Ward: RXH - PICU	188	52/33	30 (v)	93	0.45	35.3	- (6)	>5		Not recorded

Screenshot 3 - Clinical review form in the database, showing the Vital Signs of a patient, populated from the data in each facility/ EMS form

Comments

1.1/ 2.3 Initial delay around opening file, and then unclear whether initially allocated a triage colour but considerable delay >10 min to being seen likely
4.2/ 6.5/ 6.6 The clinician seems to have assessed the baby well and made the right decisions but no follow through on resus and further fluid bolus/ reassesment the child was at the facility for another 2 hours almost - and clearly remained shocked.
4.4, 4.5, 4.7, 4.9 no oxygen given, poor IO access/ stabilization, no antibiotics given (even though suggests aspiration) and temperature management not considered although temp already 35.
5.3/ 6.2 Consultation to offsite/ receiving facility not considered, and referral letter written but not sent with baby
6.4 PFS should have done this transfer - unclear if they were contacted and unavailable hence ALS transfer
6.8 apparently no verbal or otherwise handover to EMS staff by CHC

Peter Hodkinson

Frustrating as the clinician seems to have made the correct assesment and had the intent to resus and manage well but no follow through/ re-e4valuation of obviously critical neonate.

Lee Wallis

where to start? so many problems here
why is the clerk asleep? delays in folder. delays in being assessed. delays in calling ems.
children <1 month are red on SATS
no reassessment. inadequate treatment

etc etc

Andrew Argent

Delays because of sleeping clerk. Inappropriate triage, triaged orange when clearly red. Good initial assessment, but then inadequate resuscitation, no administration of antibiotics, prolonged stay when needed immediate referral.

Screenshot 4 Free text comments by each reviewer with respect to an individual health facility within a case

Standards

Level of Facility: CHC 24hr

Standards Met:

(1.3) General/Triage: Triage system in use
(2.2) Documentation: Doc time triage/first assessed
(2.3) Documentation: Doc time seen by HCP
(2.7) Documentation: Doc HCW name
(3.1) Gastro: Gastro HGT at intial assessm [IMMED]
(3.3) Gastro: Doc of signs&severity
(3.4) Gastro: ID&Doc signs shock
(3.8) Gastro: Well nourished 20 ml/kg 1/2 DD IV
(3.11) Gastro: HGT check&Mx if >=10%
(3.12) Gastro - Shocked: IV or IO access
(3.13) Gastro - Shocked: Unable site IV/IO then NG 30ml/kg/hr
(3.15) Gastro - Shocked: HGT check&Mx
(8.1) Referral: Early EMS contact by PHC/ CHC level
(8.3) Referral: Referal letter contents
(8.4) Referral: Acceptance of any critical child by L2/3

Standards Not Met:

(1.1) General/Triage: Entry to facility - eyeball assessment [5min]
(1.2) General/Triage: Fast track for paeds
(1.4) General/Triage: Triage RED - Mx by senior HCP [IMMED]
(1.5) General/Triage: Oxygen therapy Red in [5min]
(2.1) Documentation: Doc time arrival
(2.4) Documentation: Doc time Rx commenced
(2.5) Documentation: Doc weight
(2.6) Documentation: Doc time date assess/treat
(3.2) Gastro: Oxygen to Shocked Gastro [IMMED]
(3.10) Gastro: Oxygen admin if >=10%
(3.14) Gastro - Shocked: Shock Mx 20ml/kg NS repeated
(3.16) Gastro - Shocked: 2nd IV bolus&look cause
(3.17) Gastro - Shocked: 3rd IV bolus&call help
(3.18) Gastro - Shocked: Oxygen to all shocked
(8.2) Referral: Referal communications for critical paeds
(8.5) Referral: Facility handover to/from EMS
(8.6) Referral: EMS communication to rec facility

Documentation Missing:

(1.1) General/Triage: Entry to facility - eyeball assessment [5min]
(1.2) General/Triage: Fast track for paeds
(1.5) General/Triage: Oxygen therapy Red in [5min]
(2.1) Documentation: Doc time arrival
(2.5) Documentation: Doc weight
(3.2) Gastro: Oxygen to Shocked Gastro [IMMED]
(3.10) Gastro: Oxygen admin if >=10%
(3.18) Gastro - Shocked: Oxygen to all shocked

Screenshot 5 Graded Standards Applicable to a Facility

Clinical Review (073)

Combined Modifiable Factors

Facility	Level	Modifiable Factors	Impact
Facility/Ward: CHC - [redacted] Community Health Clinic		FACILITY: Accessibility of Emergency Care area/ personnel (1.1)	Minor/Moderate impact
		TRIAGE: Other - specify (2.3)	Minor/Moderate impact
		MANAGEMENT: Resuscitation not done/ inadequate for shocked pt (4.2)	Major impact
		MANAGEMENT: Ventilatory Issues (4.4)	Minor/Moderate impact
		MANAGEMENT: Circulatory issues (4.5)	Minor/Moderate impact
		MANAGEMENT: Antibiotic therapy (4.7)	Major impact
		MANAGEMENT: Temperature Mx (4.9)	Minor/Moderate impact
		CONSULTATION: No consultation to offsite specialists (5.3)	Minor/Moderate impact
		REFERRAL: Communications with receiving facility (6.2)	Minor/Moderate impact
		REFERRAL: Inappropriate referral mechanism (eg taxi/ private trnsprt) (6.4)	Not known
		REFERRAL: Inadequate stabilization for transfer (6.5)	Major impact
		REFERRAL: Ongoing monitoring/ management while awaiting transfer (6.6)	Minor/Moderate impact
		REFERRAL: Other (6.8)	Minor/Moderate impact
		COMMUNICATION: Explanation to caregiver (7.1)	Minor/Moderate impact
		DOCUMENTATION: Missing/poorly documented information (10.2)	No impact
Ambulance Transfer: CHC - [redacted] Community Health Clinic		EMS: Dispatch time delay (8.4)	Minor/Moderate impact
		EMS: Inappropriate vehicle/ crew/ equipment (8.7)	Not known
		MANAGEMENT: Circulatory issues (4.5)	Minor/Moderate impact

Screenshot 6 - Aggregated modifiable factors and their grading's for a case

Global Assessment of Care

Facility	Consensus Grade
Facility/Ward: CHC - [redacted] Community Health Clinic	Poor Peter Hodkinson: Poor, Lee Wallis: Poor, Andrew Argent: Poor, Steve Reid: Poor
Ambulance Transfer: CHC - [redacted] Community Health Clinic	Poor Peter Hodkinson: Poor, Lee Wallis: Poor, Andrew Argent: Poor, Steve Reid: Poor
Facility/Ward: RXH - Med Reg (S12)	Fair Peter Hodkinson: Fair, Lee Wallis: Poor, Andrew Argent: Poor, Steve Reid: Fair

Aspect	Consensus Grade/Assessment
Global Assessment	Poor, Clinical Consensus: Poor Peter Hodkinson: Fair, Lee Wallis: Poor, Andrew Argent: Poor, Steve Reid: Poor, Clinical Consensus: Poor
Avoidability of Death	Insufficient data (3 responses) Peter Hodkinson: , Lee Wallis: Potentially avoidable, Andrew Argent: Potentially avoidable, Steve Reid: Potentially avoidable, Clinical Consensus:
Avoidability of ICU	Not avoidable, Clinical Consensus: Not avoidable Peter Hodkinson: Not avoidable, Lee Wallis: Not avoidable, Andrew Argent: Not avoidable, Steve Reid: Not avoidable, Clinical Consensus: Not avoidable
Avoidability of Severity	Potentially avoidable, Clinical Consensus: Potentially avoidable Peter Hodkinson: Potentially avoidable, Lee Wallis: Potentially avoidable, Andrew Argent: Potentially avoidable, Steve Reid: Potentially avoidable, Clinical Consensus: Potentially avoidable
Significant Outside Issues	Yes, Clinical Consensus: Yes Peter Hodkinson: Possibly, Lee Wallis: Yes, Andrew Argent: Possibly, Steve Reid: Yes, Clinical Consensus: Yes

Screenshot 7 - Clinical Review Form, showing assessments of each reviewer (this data only available retrospectively to co-ordinators - not to blinded reviewers)

XI. PAEDIATRIC EMERGENCY CARE STANDARDS:

Contents

1 STRUCTURE & EQUIPMENT
1.1 EQUIPMENT & DRUGS IN FACILITIES FOR PAEDIATRIC RESUSITATION
1.2 STAFFING
2 PROCESS / DOCUMENTATION
2.1 RECEPTION/ TRIAGE
2.2 REFERRAL
2.3 DOCUMENTATION
2.4 STANDARDS FOR TERTIARY HOSPITAL/ ICU REFERRALS
3 GASTRO-ENTERITIS
3.1 Shocked Child with GE
4 RESPIRATORY DISTRESS
4.1 General Management of Respiratory Distress
4.2 Croup
4.3 Pneumonia
4.4 Asthma
5 FEVER/ SEPTIC SHOCK/ MENINGITIS
5.1 Fever (measured temperature>38 or history of recent fever)
5.2 Septic Shock
6 CONVULSIONS & COMA
6.1 Convulsions
6.2 Coma
7 Polytrauma
7.1 Head Injury
7.2 Orthopaedics
7.3 BURNS

Definitions and Structure Of Standards: Standards of Care were developed for the PTC project through a consensus process described in detail in subsequent chapter. Below are the definitions, and abbreviated lists of standards and their grading (through an expert consensus process) for facilities (of all levels) and EMS transfers.

A. Grading of Standards

critical - life threatening essential issues of absolute and time critical importance
important - issues that need to be addressed but perhaps without the acuity and clear link to outcome of individual cases
necessary - issues such as documentation and classification that are necessary in the system but have less impact on individual outcome

B. Standard Met or Not Met *(only the applicable standards will be entered and will be prepopulated into the clinical review in 2 lists – either standards met or not met. Each of these will then have a further "rating" of the documentation relevant to the standard.*

0= not applicable - this will be the default on all the standards not listed/ graded
1=Not met - Not documented, OR no clinical, timeline, circumstantial or reported evidence that would support the standard having been met.

2 = Standard Met- Clear documentation that the standard met, or clear clinical response, timeline, circumstantial or report from the mother giving strong evidence that the standard was met

C.**Documentation** *(will only apply to those standards that are applicable i.e.1 or 2 above)*

0 = not applicable - default

1=none – could not be traced or not present in notes despite applicability to case and review

2= avail but poor - significant information missing, illegible or missing documents within notes

3= avail, clear and providing support for standards (or lack there-of)

1. STRUCTURE & EQUIPMENT

EQUIPMENT & DRUGS IN FACILITIES FOR PAEDIATRIC RESUSITATION

The Emergency Medicine Society of SA (EMSSA) guidelines for Resuscitation Trolley Equipment and Drugs, as appropriate to the level of the facility, scope of practice of the healthcare provider and the Western Cape Package of Care will be taken as the standard. This can be accessed at
http://emssa.org.za/documents/em006.pdf

STAFFING

a) All health care staff working in facilities where children present must be trained in paediatric basic life support.
b) At least one EC nursing staff member in each facility should be IMCI/ ETAT/ APLS/ PALS or equivalent trained.
c) At least one doctor in each facility should have APLS/ PALS or equivalent training
d) Regional networks will be in place to develop protocols to stabilise and transfer children to a PICU.
e) All facilities managing emergency paediatric patients should have a link to a designated central or regional paediatrician for liaison.

EMS SPECIFIC STDS:

f) All staff working on ambulances must be trained, and current, in the latest paediatric basic life support techniques and protocols.
g) All ALS practitioners should have PALS /APLS or equivalent training.
h) Ambulance staff affecting inter-facility transfers of critically ill children should be ALS trained

2. PROCESS / DOCUMENTATION

RECEPTION/ TRIAGE

a) Every child entering the emergency unit of a healthcare unit should have a brief look/ eyeball inspection by an assigned and appropriately trained person (ideally a healthcare provider with IMCI/ETAT or SATS training) within 5 minutes of arrival.
b) Where feasible a separate queue/ area or a fast track system will be in place for the assessment of sick & injured children.
c) Children with “danger signs” IMCI, or “emergency signs” ETAT, or “red” classification (SATS) are be seen IMMEDIATELY by the most senior healthcare provider available.

d) Children with "orange" classification (SATS) are be seen within 10 minutes.
e) A universally agreed and standardized system of triage/ prioritisation should be in place and applied to all children entering any health care facility.
f) Children who wait more than 2 hours following triage to be seen should be re-triaged.
g) Critically ill or injured children will be treated in a designated resuscitation area with appropriate paediatric resuscitation equipment.
h) Information on the triage system in use as well as danger/ emergency signs will be displayed in the reception area of health care facilities for parents/ carers' information.
i) Supplementary oxygen therapy is provided to all children with danger/ emergency/ red signs within 5 minutes of arrival
j) Requirements for analgesia should be assessed, and treatment of pain delivered within 20 minutes (according to standard guidelines).

IMCI "Danger Signs": cyanosis, unconsciousness, lethargy, floppiness, convulsions, severe chest indrawing, stridor in a calm child, dehydration, purpura/petechiae
ETAT "Emergency Signs": Airway, Breathing, Circulation, Coma, Convulsion, Dehydration
SATS under review/ development in parallel with this process

EMS SPECIFIC

k) DISPATCH OF EMS CREW:
l) All emergency calls, given a priority 1 status (*i.e.* highest priority and urgency), should have a prehospital healthcare provider on scene to assist the patient within 15 minutes of the Communications Centre receiving the call
m) Every child being transported by an ambulance should be assessed and triaged by a prehospital healthcare provider.
n) Ambulance crew should be aware of the limitations of their experience and scope of practice and call for assistance when necessitated by a patient's condition, age or location.
o) Prehospital management of children classified as "red" according to SATS must be treated by the most senior healthcare provider available. ALS Paramedic to be requested if not already actively managing the patient.
p) Critically ill or injured children will be treated with appropriate paediatric resuscitation equipment.
q) Information on the triage system in use as well as danger/ emergency signs will be displayed in all ambulances.
r) Supplementary oxygen therapy is provided to all children with danger/ emergency/ red signs immediately on arrival of a prehospital healthcare provider.

REFERRAL

a) Practitioners managing critical and unstable paediatric patients (especially at clinic or CHC level) should contact EMS early and request Paediatric Flying Squad or ALS support and where necessary support/ advice from EMS on call doctor regardless of referral/ acceptance status.

b) Appropriate referral of critical patients according to unit protocols needs to be made by the treating health care practitioner with telephonic (radio) communication to the receiving practitioner/ facility when the patient is unstable or critically ill (SATS RED or ETAT/IMCI Danger)
c) Standard referral letter and all information (X-ray, laboratory) and documentation to accompany patient including: date/ time/ referring institution/ child's name/ age/ history/ vital signs (HR, RR, Temp, Sats (or CRT) and BP where appropriate)/ assessment/ treatment/ name of HCP referring.
d) No critically ill or injured child at a Level 1 facility (City Health Clinic; CHC; or District Hospital) will be refused by a Level 2 (Regional Hospital) or 3 (Tertiary Hospital) facility unless clear and immediate alternative referral pathways are made by the receiving facility.
e) Every patient transferred by EMS/ ambulance must be formally handed over and received by a Doctor/Nursing Sister through verbal and written communication at the referring and accepting institution.

EMS SPECIFIC

<u>DISPATCH</u>

f) Paediatric Flying Squad (PFS) should be activated to affect the inter facility transfer of all Red (according to SATS) code patients as well as those identified on the Paediatric Emergency Referral Call Out Pathway document.
g) Should the PFS not be available, then an alternative ALS crew should be activated (with the necessary equipment) to affect the transfer.
h) Expected arrival of critically ill patients is to be communicated to the receiving facility by METRO communication Centre by either phone call or radio communication (where available)

<u>DISPOSITION (APPLYING TO EMS PRIMARY TRANSFER FROM SCENE):</u>

i) The patient should be taken to the closest, most appropriate, health care facility following the guidelines provided by SATS and the Paediatric Emergency Referral Call Out Pathway protocol.
j) In the event of a medical dispute, the METRO medical officer on duty will act as arbitrator in patient referral.

<u>HANDOVER:</u>

k) Every patient must be formally received and handed over by the EMS staff through verbal and written communication at the referring and accepting institution.
l) The minimum handover information required is stated in the DeMIST protocol.

DOCUMENTATION

a) Documentation of time of:
    i. arrival at the health care facility (as close to entry as possible)

ii. triage/ first formal assessment
iii. when first seen by a health care provider
iv. when treatment commenced

b) Documentation of admission weight
c) Documentation of the time and date of each assessment/ treatment decision in the notes.
d) Documentation (printed/ legibly) of the health care workers name in the notes.

EMS SPECIFIC

e) Documentation of time of:
   i. Call received by control centre
   ii. Dispatch of EMS crew
   iii. Arrival at the patient's side
   iv. Triage/ first formal assessment
   v. Drug administration
   vi. Departure from scene/ referring facility
   vii. Arrival at receiving facility
d) Documentation will include: medical history (e.g.SAMPLE, mechanism of injury), assessment (e.g.primary/secondary survey, pain assessment OPQRST, vital signs), treatment and any other relevant factors. It should reflect a clear picture of the patient's condition and the care provided.
e) Documentation should be legible to others and reflect the health care workers name.

STANDARDS FOR TERTIARY HOSPITAL/ ICU REFERRALS

a) Time from ICU request to assessment by ICU staff 1 hour
b) Time from ICU bed request (within RCWMCH) for a ventilated child to ICU admission – 2 hours
c) Time from ICU bed request (within RCWMCH) for a non-ventilated child to ICU admission – 4 hours
d) Maximum time for ventilation of child outside of ICU at regional hospital – 24hrs
e) Monitoring of ventilated/ critical patient awaiting ICU outside of ICU:
   i. Staffing - ratio Registered Nurse to patient 1:1
   ii. Continuous monitoring and documentation of vitals Sats/P/BP every 15 minutes
   iii. Appropriate paediatric ventilation and monitoring equipment for ventilation outside of ICU
f) Availability of consultant when managing doctor perceives a need to discuss/ review with a specialist for a patient – 15 minutes

3. GASTRO-ENTERITIS

a) Children presenting with diarrhoea must have documentation of dehydration signs and severity (lethargic/ sunken eyes/ skin pinch> 3 sec)
b) Identification & documentation of signs of shock (cold hands/ CRT > 3sec/ pulse weak & rapid)

c) Use of a dedicated oral rehydration therapy (ORT) area in each facility with appropriate equipment and facilities
d) Use of Western Cape Paediatric Gastroenteritis Protocol for dehydration / diarrhoea management

Shocked Child with GE

a) Diarrhoea patients in shock (cold hands/ capil refil> 3 sec/ weak & fast pulse) must be treated with IV or IO N/S or R/L bolus of 20ml/kg within 10 minutes of arrival (10ml/kg for malnourished child) , and repeated to response.
b) HGT will be checked and managed appropriately if <3 mmol/l
c) In shocked children who remain shocked after first IV bolus, repeat and consider other causes of shock
d) In shocked children who remain shocked after second IV bolus, repeat and consult a senior doctor or referral centre urgently.
e) Give oxygen to all shocked children with GE.

4. RESPIRATORY DISTRESS

General Management of Respiratory Distress

- Identification (and documentation of signs) of a problem airway in a child using: obstructive noises, colour (cyanosis), sats (where available), RR.
- Identification and documentation of severity of respiratory distress using: RR, Recessions, accessory muscle use, head bobbing, inability to feed, HR, and LOC/ lethargy.
- Basic Airway Manoeuvres to be performed for an obstructed airway include: chin lift, oro-pharyngeal airway and suction.
- Oxygen administration to all children with sats<92%, poor colour or cyanosis, using as appropriate and available: nasal prongs, non rebreather paediatric face mask or bag valve mask
- Advanced Airway Management
    - should be provided immediately if indicated and it can be performed by an appropriately experienced HCP (with rapid sequence induction when appropriate)
    - Bag-Valve-Mask assisted ventilation should be used as an alternative to advanced airway management where there are no skills or facilities for intubation
    - Use of correct size ETT at correct depth
    - Confirmation (with documentation) of ETT placement in trachea
    - Ventilator setup appropriate for age/weight/ condition and documented
    - Post intubation care including securing ETT, position checks, NGT insertion, CXR, and sedation
    - Documentation of advanced airway management process including equipment (tube size, depth; ventilator settings), timing, drugs (if any) used and complications arising – consider use of a checklist

Croup

a) Documentation of signs of severity
b) Adrenaline nebulisations given to children when appropriate (grade 2/3/4)
c) Correct prescription of steroids. (not for EMS)

Pneumonia

a) Documentation of signs of severity of pneumonia
b) Classification of pneumonia (moderate/ severe/ very severe).
c) Management of severe pneumonia with appropriate parenteral antibiotics given within 30 minutes of assessment by HCP.
d) Correct dose of antibiotics prescribed to children with pneumonia where indicated

Asthma

a) Correct assessment of severity of asthma
b) Documentation of signs of severity (RR, indrawing, sats, air entry, ability speak, exhaustion).
c) Administration of a nebulized bronchodilator and oxygen within 5 minutes of triage.
d) Administration of steroids for moderate/ severe asthma exacerbation.
e) Correct dose of bronchodilator prescribed
f) Correct dose of steroid prescribed.
g) On discharge: Check inhaler technique (with spacer when appropriate), advice on dosing frequency, adequate supplies of drugs, advice on when to return if worsening

5. FEVER/ SEPTIC SHOCK/ MENINGITIS

Fever (measured temperature>38 or history of recent fever)

a) Temperature documented in notes at time of triage
b) Urine testing for all infants less than 3 months of age with fever
c) Urine testing of children with fever and no obvious cause for fever
d) Administration of antipyretics to all children with temperature $>38^{5}$ within 30 minutes of assessment of temperature
e) Administration of first dose of parenteral antibiotics where appropriate within 60 minutes
f) Documentation of evidence of meningism or associated signs of meningitis in children with fever and non-blanching rash.

Septic Shock

a) Early recognition of children with septic shock or likely to develop septic shock
b) Correct assessment and documentation of shock (colour, periphery temperature, HR, pulse volume, CRT)
c) Early adequate IV or IO access obtained
d) Early IV fluid bolus (N/S or R/L 20ml/kg) within 10 minutes of triage
e) Blood Sugar (HGT) checked early, documented and appropriately managed
f) Time from triage to administration of parenteral antibiotics less than 30 minutes

g) Inotropes/ vasopressors where shock unresponsive to fluids
h) Referral of all children identified with septic shock to appropriate facility (PICU)

6. CONVULSIONS & COMA

Convulsions

a) Administration of oxygen (high flow face mask with reservoir)
b) Measurement of HGT immediately , documented and appropriately managed
c) First prescription appropriate anticonvulsant by appropriate route
d) Correct dose of appropriate anticonvulsant given
e) Neonatal convulsions for an infant less than 2 weeks of age controlled with phenobarbitone
f) Correct dose of phenobarbitone for neonatal convulsions
g) Seizures not controlled with 2 doses of benzodiazepines managed with IV/IM phenytoin/ phenobarbitone
h) Appropriate post convulsion management: observation/ admission/ follow up/ investigations where necessary

Coma

a) Correct assessment and documentation of level of consciousness (GCS or AVPU)
b) Airway protection manoeuvres as appropriate to level of consciousness or other indications
c) Administration of oxygen (high flow face mask with reservoir)
d) Measurement of HGT immediately, documented and appropriately managed
e) Administration of appropriately diluted glucose (5ml/kg) if HGT < 3 mmol
f) Administration of appropriate anticonvulsant where necessary
g) Ongoing neuro-observations for the child as appropriate
h) Brain imaging requested as appropriate
i) Referral of all children with coma to appropriate facility

7. Polytrauma

a) All injured children will be given adequate and appropriate analgesia as part of the primary survey/ initial resuscitation
b) All injured children will remain with their parents/carers as far as possible throughout the emergency care period.
c) Children involved in a high impact motor vehicle collision (or other mechanism with suspected neck injury) will receive appropriate spinal protection and immobilisation.
d) All children with signs of shock should have intravenous/ intraosseous access obtained as soon as possible.
e) Once IV/IO access has been achieved, children with signs of shock should be treated with (preferably warmed) fluid bolus of 10ml/kg Ringers Lactate or Normal Saline.
f) In shocked children unresponsive to multiple boluses of fluid (40ml/kg) for shock administer blood where available.

g) All children with severe injuries who may require operative management should be kept nil per os.
h) The possibility of Non Accidental Injury should be considered for all children and appropriate procedures must be followed in suspected cases including documentation.
i) Tetanus toxoid administration should be considered for all open wounds.

Head Injury

a) All children with possible or suspected head injury should have an accurate documented GCS or AVPU at first contact with health provider.
b) Children with an indication for a CT brain should be identified (as per Provincial Head Injury Guidelines) and a CT brain expedited.
c) Airway protection manoeuvres as appropriate to level of consciousness or other indications should be provided early.
d) Intubation should be considered where indicated and it can be performed by an appropriately experienced healthcare provider (with rapid sequence induction when appropriate). BVM ventilation is an alternative where there are no skills or facilities for intubation.
e) The use of standard neuro-observation documentation to regularly document vital signs and GCS/ AVPU as appropriate.
f) Transfer of head injury patients to appropriate facility as per Provincial Head Injury Guidelines
g) Neurosurgical review where indicated as soon as appropriate for head injured children.

Orthopaedics

a) Early immobilisation and reduction of fractures should be performed.
b) Use of appropriate procedural sedation for all interventions
c) Antibiotics within 30 minutes of arrival for all open fractures and complicated wounds.

Burns

a) Documentation/illustration of burn wounds including:
   i. Region(s) and area (% body surface area)
   ii. Depth
   iii. Time of the burn
   iv. Mechanism
b) Management of severe burns according to the SA Burns Society Guidelines
c) For severe burns administer IV fluids using the Parklands formula (3.5 x weight x %burn)
d) For severe burns appropriate analgesia should be given within 20 minutes
e) In children with burns, search for and recognise signs of inhalational burns.
f) Consider early intubation and ventilation of children with inhalational burns/facial burns/neck burns and extensive chest burns.
g) Severe burns should initially be dressed with an appropriate occlusive dressing early

h) Escharotomies should be performed appropriately when deemed necessary by experienced personnel
i) For severe burns, Red Cross Children’s Hospital referral criteria should be utilised.

XII. MODIFIABLE FACTORS

Grading and Definitions for Modifiable Factors

A. **Impact of Modifiable Factors** – for each facility, transfer or ward within a hospital (of note is that the numbers and sequence of these categories do not represent a score – they are categories only)

0=No Impact – factor which has no individual or cumulative negative impact on the outcome of this case (*this will be the default) (and for all the modifiable factors which are not linked to the case)*
1=Not known - cannot be established or estimated given facts known about scenario
2=Minor/ Moderate Impact – factor which on its own had minimal negative impact on the outcome **but** may have caused some morbidity and/ or extended the hospital/ PICU stay
3=Near Miss - unplanned event that did not have major impact– but had the potential to do so. Only a fortunate break in the chain of events prevented an injury, fatality or damage
4=Major Impact – factor which had clear negative impact on the outcome for the patient (worsened mortality or morbidity). Directly and overwhelmingly important factor in the severity of illness/ death.

B. **Global assessment/ grading of care** for each facility/ transfer/step of pathway and overall

1=poor - Health Care which was clearly below the average expectations of the facility/ HCP
2=fair – Health Care of an average level expected of the facility/ HCP
3= good – Health Care at an excellent level above average expectations

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MODIFIABLE FACTORS FOR FACILITY/ EMS

1. **FACILITY**
    - 1.1. Accessibility of Emergency Care area/ personnel
2. **TRIAGE**
    - 2.1. Inadequate assessment at triage
    - 2.2. Triage mechanism misses critical patient
    - 2.3. Other
3. **INITIAL ASSESMENT BY Health Care Practitioner**
    - 3.1. Missing key findings (history/ clinical)
    - 3.2. Inadequate assessment/ interpretation of severity
    - 3.3. Investigations inadequate
    - 3.4. Investigations excessive
    - 3.5. Missed/ incorrect diagnosis
    - 3.6. Other
4. **MANAGEMENT**
    - 4.1. Delay in critical management decisions
    - 4.2. Resuscitation not done/ inadequate for shocked pt
    - 4.3. Airway Issues
    - 4.4. Ventilatory Issues
    - 4.5. Circulatory issues
    - 4.6. HGT assessment & Mx
    - 4.7. Antibiotic therapy

4.8. Analgesia
4.9. Temperature Mx
4.10. Electrolyte abnormality Mx
4.11. Trauma Immobilization
4.12. Delay in disposal decisions
4.13. Other

5. **CONSULTATION**
   5.1. Inadequate supervision of junior staff
   5.2. No consultation to on site seniors
   5.3. No consulation to offsite specialists
   5.4. Senior review of patients (e.g.ward round) inadequate
   5.5. Delayed consultation
   5.6. Other
6. **REFERRAL**
   6.1. Inappropriate referral destination
   6.2. Communications with receiving facility
   6.3. Call/ information given to EMS about transfer
   6.4. Inappropriate referral mechanism (e.g.taxi/ private trnsprt)
   6.5. Inadequate stabilization for transfer
   6.6. Ongoing monitoring/ management while awaiting transfer
   6.7. Referral Delay
   6.8. Other
7. **COMMUNICATION**
   7.1. Explanation to caregiver
   7.2. Communication death issues
   7.3. Other
8. **EMS** **EMS MODIFIABLE ISSUES**
   8.1. Communication with call centre at initiation of transfer
   8.2. Communication from control to dispatched crew
   8.3. Prioritization of call out
   8.4. Dispatch time delay
   8.5. Transfer time excessive
   8.6. Response time delay
   8.7. Inappropriate vehicle/ crew/ equipment
   8.8. Inadequate stabilization for transfer
   8.9. Inadequate assessment before transfer
   8.10. Inadequate monitoring en route
   8.11. EMS clinical management decision
   8.12. EMS disposal decision
   8.13. Other
9. **OPERATING THEATRE** (those not covered above)
   9.1. Anaes Pre-op Assesment Inadequate
   9.2. Anaes Senior not called pre-op
   9.3. Surg Pre-op Assesment Inadequate

9.4. Surg Senior not called pre-op
9.5. Delay pre-op
9.6. Anaesthetic technique
9.7. Fluid Management
9.8. Surgical technique
9.9. Delay on table
9.10. Delay in calling senior in emerg
9.11. Recovery Process issues
9.12. Delay in transfer out
9.13. Other

10. DOCUMENTATION

10.1 Missing date/ times
10.2 Missing / poorly documented information
10.3 other document issues

11. **RADIOLOGY**

11.1 Delay awaiting radiology
11.2 Delay in performing radiology
11.3 Delay reporting radiology
11.4 Radiology findings missed/ misinterpreted
11.5 other

12. ADVICE TO PARENTS

12.1 No documentation of advice given
12.2 No documentation but parents recall advice

XIII. VISUALIZATION OF EXPERT REVIEWER GRADINGS FOR EACH CASE

Table 0-13 gives a visual representation of each reviewer's gradings for every case enrolled, looking just at global quality of care for each of the 282 cases (in the order that they were collected).

Colour key is shown in Table 0-12:

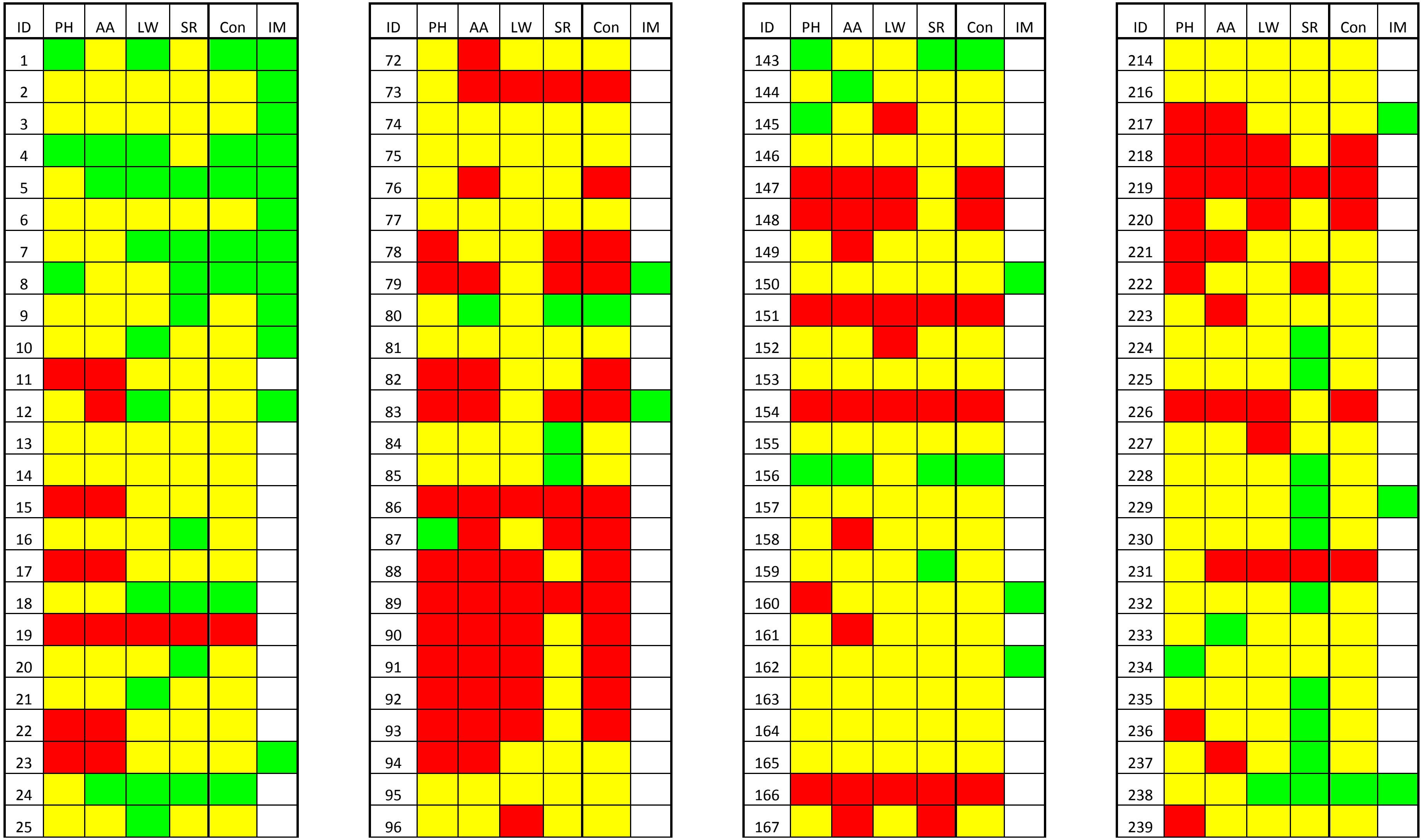
Table 0-12 Grading schematic key

Colour	Reviewer Assessment
	Poor
	Fair
	Good
	No external review

The four reviewers are abbreviated:

PH	Peter Hodkinson	Clinical Fellow
AA	Andrew Argent	Paediatric Intensivist
LW	Lee Wallis	Emergency Medicine
SR	Steve Reid	Primary Health Care
IM	Ian Maconochie	External Reviewer (Paediatric Emergency Medicine)

Table 0-13 Visualization of reviewer gradings for global quality of care and consensus process



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